CHALLENGES IN AUTISM SPECTRUM DISORDER INTERVENTION: DIAGNOSIS, BEHAVIOR MANAGEMENT AND ETHICAL PRACTICE IN CHANGING TIMES

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#### Who am I?

#### What will we be talking about?

Changes in ASD diagnoses with the DSM-5

- Fundamentals of behavioral intervention for challenging behaviors associated with ASD
- Changes in behavioral interventions with the repeal of the Hughes Bill, the passage of AB86 and renewed focus on the IDEA 2004
- Barriers to effective behavioral intervention
- Ethical challenges in delivering behavioral services in the current ASD environment
- Troubleshooting your behavioral challenges

# Changes in Autism Diagnosis

#### Autism - Then

- First described by Leo Kanner in 1943
  - Extreme social deficits/autistic aloneness
  - "insistence on sameness"
- Shortly thereafter, Hans Asperger described a similar group of children, but without cognitive impairments
  - This became known as Asperger's Syndrome or Disorder
- For years, considered as single disorders, with different levels of severity
- More recently, thought of as a spectrum of disorders, the Autism Spectrum Disorders (ASD)

#### Autism Spectrum Disorder - Now

- A neurodevelopmental disorder
- Neurologically based
- Present at, or after a brief period of typical development
- Most recent estimate 1 in 88 children
- 4:1 male to female ratio
  - 1 in 54 boys and 1 in 252 girls
- 38% have intellectual disabilities
- Cost as much as 1.5 to 3.2 million over a lifetime

Pervasive Developmental
 Disorders in the DSM-IV-TR
 In the past (DSM-IV-TR), this category of

Autism Spectrum Disorders included:

Autistic disorder

- Asperger's disorder
- Childhood disintegrative disorder
- Rett's disorder
- Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)

#### Diagnostic Criteria for Autistic Disorder in the DSM-IV-TR

- A. A total of six (or more) from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
  - (1) qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) marked impairment in the use of multiple nonverbal behaviors, such as eyeto-eye-gaze, facial expressions, body postures and gestures to regulate social interaction
    - (b) failure to develop peer relationships appropriate to developmental level
    - (c) a lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest)
    - (d) lack of social or emotional reciprocity

## Autistic Disorder – DSM-IV-TR

- (2) qualitative impairments in communication, as manifested by at least one of the following:
  - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime)
  - (b) in individuals with adequate speech, marked impairments in the ability to initiate or sustain a conversation with others
  - (c) stereotyped and repetitive use of language or idiosyncratic language
  - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

#### Autistic Disorder – DSM-IV-TR

- (3) restricted, repetitive and stereotyped patterns of behavior, interests and activities as manifested by at least one of the following:
  - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
  - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
  - (d) persistent preoccupation with parts of objects

 B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language, as used in social communication, or (3) symbolic or imaginative play

 C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

#### Asperger's Disorder (Syndrome) – DSM-IV-TR

- Similar impairments in social interaction and restricted, repetitive and stereotyped patterns of behavior, interests and activities, with
  - No clinically significant impairment in social, occupational or other important areas of functioning
  - No clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction) and curiosity about the environment
  - No clinically significant general delay in language

## Other PDD's in DSM-IV-TR

#### Childhood Disintegrative Disorder

• With a pattern of normal development to age 2, with clinically significant loss of functioning thereafter

#### Rett's Syndrome

Another form of progressive loss after typical development

#### Other PDD's in DSM-IV-TR

 Pervasive Developmental Disorder, Not Otherwise Specified (PPD-NOS)

- Presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology or subthreshold symptomatology or all of the above
- Interestingly, PDD-NOS, a term which designates those who do not meet the full criteria for Autistic Disorder, fell into the category of an Autistic Spectrum Disorder within DSM-IV-TR

#### Diagnosis in the new DSM-5

 Newest edition of the Diagnostic and Statistical Manual of Developmental Disorders (5<sup>th</sup> edition), published by the American Psychiatric Association

- Changes from past editions with significant changes in the diagnosis of Autism
  - No longer under Pervasive Developmental Disorders
  - Now Autism Spectrum Disorder
  - Asperger's Syndrome is gone as a separate diagnosis, as is Childhood Disintegrative Disorder, Rett's Disorder and PDD-NOS

#### Reason for the changes

- Lack of specificity in the DSM-IV diagnoses, especially those for Asperger's disorder and PDD-NOS
  - 2,027 possible combinations of criteria in the DSM-IV-TR to arrive at a diagnosis of any of the three ASD's
  - Only 11 possible combinations of criteria in DSM-5
- Essential connection between communication and social interaction
  - Two separate clusters in DSM-IV and one cluster in DSM-5
- Acknowledgement that the ASD's share an underlying basis

   a disorder with degrees of severity
- Concern for over diagnosis, with resultant dramatic unsupportable increases in incidence (1 in 88)

# ASD in the DSM-5 (299.0)

In the category of Neurodevelopmental Disorders

- Two symptom clusters
  - Deficits in social communication and social interaction across multiple contexts
  - Restricted, repetitive patterns of behavior, interests or activities
- Present in the early developmental period
  - May not become fully manifest until social demands exceed limited capacities
  - May be masked by learned strategies later in life
- Limited and impaired ability to successfully function in a social world
- Not better explained by intellectual disability or global developmental delay

# Symptom Clusters in ASD

Social communication and social interaction
 Combined together in this edition; separate clusters in the previous DSM-IV-TR

#### Must include <u>all of the following</u>:

- Deficits in social-emotional reciprocity, ranging 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
- Examples are illustrative, not exhaustive

## Symptom Clusters in ASD

 Social communication and social interaction, continued

- Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and non-verbal communication
- Again, examples are illustrative, not exhaustive

#### Symptom Clusters in ASD

 Social communication and social interaction, continued

 Deficits in developing, maintaining and understanding relationships, ranging, for example, from difficulties adjusting behaviors to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers

Again, examples are illustrative, not exhaustive

Level of severity for social/communication symptom cluster

- Level 1 "Requiring support"
  - Without supports in place, deficits in social communication cause noticeable impairments
  - Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others

May appear to have decreased interest in social interactions

# Level of severity for social/communication symptom cluster

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 interaction

 Reduced or abnormal responses to social overtures from others

# Level of severity for social/communication symptom cluster

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

#### Symptom clusters in ASD

Restricted, repetitive patterns of behavior, including at least two of the following:

 Stereotyped or repetitive motor movements, use of objects or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)

 Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

#### Symptoms clusters in ASD

 Restricted, repetitive patterns of behavior, continued

- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)
- Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.)

Level of severity for restricted or repetitive patterns of behavior
 Level 1 – "Requiring support"

- Inflexibility of behavior causes significant interference with functioning in one or more contexts
- Difficulty switching between activities
- Problems of organization and planning hamper independence

Level of severity for restricted or repetitive patterns of behavior
 Level 2 – "Requiring substantial support"

 Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behavior appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts

Distress and/or difficulty changing focus or action

 Level of severity for restricted or repetitive patterns of behavior
 Level 3 – "Requiring very substantial support"

 Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres

Great distress/difficulty changing focus or action

# ASD in DSM-5 - Specifiers

#### Specify

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor
- Associated with another neurodevelopmental, mental or behavioral disorder
- With catatonia

#### ASD in DSM-5

 Although Asperger's disorder and PDD-NOS are no longer in DSM-5, it is specified that:

 Individual with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder or PDD-NOS should be given the diagnosis of autism spectrum disorder.

Nobody LOSES their diagnosis

 Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for ASD, should be evaluated for social (pragmatic) communication disorder

#### Social (Pragmatic) Communication Disorder (315.39 - a new diagnosis)

- Persistent difficulties in the social use of verbal and nonverbal communication
  - Deficits in using communication for social purposes
  - Impairments of the ability to change communication to match context or the needs of the listener
  - Difficulties following rules for conversation and story telling
  - Difficulties understanding what is not explicitly stated (e.g. making inferences) and nonliteral or ambiguous meanings of language
- The new PDD-NOS?

#### ASHA on SCD Diagnosis

A social communication disorder may be a distinct diagnosis or may occur within the context of other conditions, such as autism spectrum disorder, specific language impairment, learning disabilities, developmental disabilities, attention deficit hyperactivity disorder and traumatic brain injury. Other conditions (e.g., psychological/emotional disorders and hearing loss) may also impact social communication skills."

#### ASHA on SCD Treatment

#### Treatment typically

- Recognizes the importance of
  - Family involvement
    - Cultural values and norms
    - Collaboration with a variety of professionals and communication partners
    - Facilitation of peer-mediated learning
    - Continuity of services across environments
    - Addressing functional needs
    - Matching service delivery to meaningful outcomes

- Provides services that are connected with functional and meaningful outcomes, such as
  - The child being included in social settings with greater frequency
  - The child experiencing less frustration with problem solving, etc.
- Provides services in natural learning environments, to the extent possible
- Incorporates the collaborative efforts and input from families, classroom teachers, special educators, psychologists and SLP's

# The impact of changes to ASD diagnosis in DSM-5

The diagnosis of Asperger's disorder is gone
Although prior diagnoses are grandfathered in

 What is the impact on those who would have been given that diagnosis and are now ASD?
 Is a diagnosis of ASD more or less acceptable to these individuals and their families?

# The impact of changes to ASD diagnosis in DSM-5

- The diagnosis is more restrictive and it's harder for some to meet the full criteria for ASD
  - Will fewer children be diagnosed with ASD?
  - Will those with less impairments fail to be diagnosed?
  - Will children lose access to funding and services?
    - Doctors may ignore the DSM-5 and schools will continue to use eligibility guidelines rather than DSM-5 diagnoses, but Regional Centers and insurance companies will likely rely on the new diagnostic category

## The impact of changes to ASD diagnosis in DSM-5

Two recent studies give us some insight into the impact of the changes in ASD diagnosis since May 2013

#### How will DSM-5 Affect Autism Diagnosis? A Systematic Literature Review and Meta-Analysis

- Kristine M. Kuluge, Arlene M. Smaldone, Elizabeth G. Cohn in *Journal of Autism and Developmental Disorders*, February 2014 (online)
  - 31% reduction in those diagnosed with ASD, based upon evaluation of multiple studies comparing the same groups of children on DSM-IV-TR and DSM-5 criteria
    - 22% reduction in AD diagnosis
    - 70% reduction in PDD-NOS diagnosis
    - the reduction for Asperger's was not statistically significant

 A Comparison of DSM-IV PDD and DSM-5 ASD Prevalence in an Epidemiologic Sample. Journal of the American Academy of Child & Adolescent Psychiatry, 2014; DOI: 10.1016/j.jaac.2013.12.021

 Young Shin Kim, Eric Fombonne, Yun-Joo Koh, Soo-Jeong Kim, Keun-Ah Cheon, Bennett Leventhal.

#### 83% of children who received a diagnosis of autism under the DSM-IV would also receive the diagnosis under DSM-5

- 14% would be diagnosed with a Social Communicative Disorder; However:
  - No current evidence-based treatment guidelines for SCD, and
  - No guarantee of funding under this diagnosis
- Of children previously diagnosed with PDD-NOS, 71% would now be diagnosed with ASD, 22% with SCD and 7% with another non-autism disorder
- Of those previously diagnosed with Asperger disorder, 91% would now be diagnosed with ASD, 6% with SCD and 3% with another non-autism disorder
- Of those previously diagnosed with autistic disorder, 99% would now be diagnosed with ASD and 1% with SCD
- Findings suggest that most individuals with a prior DSM-IV PDD meet DSM5 diagnostic criteria for ASD and SCD.

## Impact of DSM-5

- Too soon to tell with regard to incidence and access to funding
- Not clear who will use the new criteria and who will not
  - Just as it's not clear who used DSM-IV Criteria
- Not as relevant to school-based services
  - Eligibility vs. Diagnosis

Likely to be more relevant for Regional Center and insurance-based services

## **ASD** Intervention

## Evidence-based (Behavioral) approaches to ASD intervention

- Vast literature regarding the effectiveness of a behavioral approach to ASD, especially when used as part of an Intensive Early Intervention program
- However, there are many barriers to successful ASD intervention:
  - Costly
  - Labor intensive
  - Disagreements with regard to how to define 'success'
  - It is subject to the resistance of our customers

### Challenging behavior and ASD

Not associated specifically with the diagnosis

May be associated with difficulties in communication

May be associated with ineffective environments at school and/or at home

May be associated with resistance to intervention or as a response to poor intervention

### Challenging behavior and ASD

 Challenging behaviors have broad impact upon:

Quality and quantity of intervention

- Speed and extent of skill acquisition/use
- Progress toward functional independence
- Placement options
- Access to services
- Options upon transition to adulthood
- Social relationships
- Family dynamics and cohesion

#### A Behavioral Model of Intervention for Challenging Behavior

Behaviors, both positive and negative, occur for reasons

Those reasons are found in the environments in which individuals live and work

The events which occur before behavior and the events which occur after behavior influence the future probability of that behavior

# SD R SR Image: Market Size of the state of the state

The events that occur before challenging behavior set the occasion for that behavior and the consequences that follow challenging behavior influence the probability that it will occur again in the future.

The most important thing to consider...

We manage behavior by

### INTENT or by

MISTAKE

#### Beginning the process of understanding challenging behavior

Since challenging behaviors don't generally happen all of the time (no matter how it seems to us), the first questions that we must ask when challenging behavior does occur are...

#### ■ WHY NOW (and not 10 minutes ago)?

- At this moment
- During this activity
- In this location
- With this person

WHAT FUNCTIONS OR PURPOSES DO THESE BEHAVIORS SERVE FOR OUR STUDENTS (Why do they exhibit them)?

There is a way to begin to ask these questions...

#### The functional analysis of challenging behavior

- A form of data collection to ask the question...why?
- A necessary prerequisite to the development of a behavior plan and a roadmap for the development of that plan
- The gathering of information about the relationship between the challenging behaviors of concern and the environments in which those behaviors occur
- We're looking for PATTERNS
- Those PATTERNS are our clues to the FUNCTIONS of challenging behavior what purpose they serve

## Sources of information for a functional analysis

- Direct observations
- Interviews
- Review of past interventions
- Questionnaires, checklists and other data collection
  - ABA charts
  - Motivation Assessment Scale
  - Scatterplot

#### **BEHAVIOR OBSERVATION RECORD**

NAME\_\_\_\_\_OBSERVER\_\_\_

#### BEHAVIOR

	IAVIO	<u> </u>			
Day	Date	Time	ANTECEDENTS What was happening just before the behavior?Where did the behavior happen? Who was there?	BEHAVIORS What did the person do? What did the behavior look like? Be as specific as possible.	CONSEQUENCES What happened after the behavior? What did everyone do? How did the environment change after the behavior?

SCATTERPLOT FOR																					
TARGET	BEHA	VIO	R				DATE RECORDING STARTED														
	Use the 4 codes below to indicate how each square will be filled based on the frequency of the targeted behavior that occurs during that time interval.																				
TIME	*			*					*					*							
7-7:30a																					
7:30-8																					
8-8:30	1																				
8:30-9																					
9-9:30																					
9:30-10																					
10-10:30																					
10:30-11																					
11-11:30																					
11:30-12																					
12-12:30																					
12:30-1																					
1-1:30													1								
1:30-2														1							
2-2:30																					
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5-5:30																					
5:30-6																					
6-6:30																					
6:30-7																					
7-7:30																					
7:30-8																					
8-8:30																					
8:30-9																					
DAYS	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21

Some of the functions of challenging behavior

- Escape
- Attention

Tangible items, activities, individuals

Internal stimulation/Sensory

• Others?

## What do we do with the information from the functional analysis

- We use the information about the functions of challenging behavior to develop behavior plans
- We tie the intervention to the specific function of the challenging behavior whenever possible
- Our goals are
  - to make the challenging behavior irrelevant and unnecessary;
  - to replace the challenging behaviors with socially appropriate, functionally equivalent behaviors;
  - to increase other functional skills;
  - and to alter the consequences that maintain challenging behaviors

## Strategies to reduce or replace challenging behaviors

Prevention/make it unnecessary or irrelevant

 If you know why it's happening, modify the environment to remove the triggers that cause challenging behavior to occur

 Make preventative changes in the environment before behavior occurs to make it unnecessary to it to occur

## Strategies to reduce or replace challenging behavior

Teach new, replacement behaviors which serve the same function

- Respect the communicative function of the challenging behavior, but offer an alternative
- Functionally equivalent replacement behaviors
  - As easy to perform
  - Get the same environmental payoff
  - As efficient and effective at getting that payoff
  - Or else, why should the student use the replacement behavior

## Strategies to reduce or replace challenging behavior

Reduce sources of reinforcement that are maintaining the challenging behavior

ExtinctionTime out procedures

## Strategies to reduce or replace challenging behavior

Reinforce behaviors others than the targeted challenging behaviors

The use of reinforcement in a different way
 Differential reinforcement
 DRO, DRI, DRL, DRC, etc.
 Contracts, token systems

## Four fundamental strategies that can be used in all settings for all students

- Reinforce more those things that you want to see more of
- Reinforce less those things that you want to see less of
- Pay attention to those communicative attempts by students which usually precede challenging behaviors
- Keep the kids engaged down time is a breeding ground for challenging behavior

### The end of the Hughes Bill and why that matters

## The repeal of the Hughes Bill

- As of July 1, 2013, AB86 was passed repealing the Hughes Bill, the California behavioral intervention mandate for special education students who exhibited serious behavior problems.
  - The Hughes Bill mandated the use of specific behavioral assessment and intervention methodologies for individuals exhibiting serious challenging behaviors.
- AB86 now requires behavior interventions for special education students to align more closely with federal law, as identified in the Individual with Disabilities Education Act ('IDEA'), last revised in 2004

Repeal of the *Requirement* to Conduct a Functional Analysis Assessment

- School districts are no longer required to conduct functional analysis assessments (FAA's) and develop 'Hughes Bill' behavioral intervention plans (BIP's) for students who exhibit 'serious behavioral problems.'
- Districts are required to follow federal law, which provides that IEP teams must address behavior when it impedes a student's learning or the learning of others.

May use their discretion to address behavior in a variety of ways

- Children with serious behavior problems must 'receive timely and appropriate assessments and positive supports and interventions in accordance with the IDEA'
- 'Consider the use of positive behavioral interventions and supports, and other strategies, to address that behavior.'
- The IDEA refers to BIP's. Previously, BIP's referred to Hughes Bill behavior plans and BSP's referred to non-Hughes Bill behavior plans. Now all plans can be called BIP's

- Limitations on the Use of Emergency Interventions
  - Emergency interventions may not be used in lieu of an appropriate BIP that is designed to change, replace, modify or eliminate a targeted behavior.
  - Emergency interventions may only be used 'to control unpredictable, spontaneous behavior that poses clear and present danger of serious physical harm' to a student with a disability or others and that 'cannot be immediately prevented' by a lesser restrictive response.

- Continuation of the Prohibition Against Certain Emergency Interventions
  - AB86 continues to prohibit the use of both restraint (employment of a device, material or objects that simultaneously immobilize all four extremities) and locked seclusion (except for agencies licensed and authorized to use such interventions)
  - AB86 prohibits the use of interventions that are designed or are likely to cause pain (such as electroshock) or that subject students to verbal abuse, humiliation or ridicule; that deprive students of any of their senses or of sleep, food, water, shelter or proper supervision; or that involve the use of noxious sprays or substances

- Notification of the Use of Emergency Interventions
  - School districts must still notify the student's parents, guardian or residential caregiver of the use of an emergency intervention or of serious property damage within one school day of the incident.
  - School districts must also immediately complete a behavioral emergency report (BER) documenting the details of the incident and whether or not the student has a BIP; submitted to a designated responsible administrator and placed in the student's file

- Obligation to Schedule and Convene an IEP Meeting When Emergency Interventions are Used
  - Where a student does not have a BIP in place, school districts continue to be required to schedule an IEP meeting within two school days to review the BER
  - The IEP team must review the BER to determine the necessity for a functional behavior assessment and an interim plan, pending the development of a BIP, if needed.
  - Where the student has a BIP, the IEP team must determine the need to modify the existing BIP when the incident involves a previously unseen serious behavior problem or ineffective behavior intervention.

- Behavior Intervention Case Manager (BICM) is Eliminated
  - Districts are no longer required to use a BICM when a BIP is being developed and implemented.
  - A District may, but is not required to use a Board Certified Behavior Analyst (BCBA) for behavior assessment and behavior intervention services
  - AB86 requires the Superintendent of Public Instruction to explore whether current teacher credentialing requirements include sufficient training in appropriate behavioral interventions.

## Summary - Post Hughes Bill

- With these changes, the school districts have more flexibility, consistent with AB86 and IDEA to conduct behavioral assessments and develop BIP's using 'qualified' staff, other than a BCBA.
- Eliminates the obligation of a district to conduct an FAA and develop a BIP, even for students who exhibit 'serious behavioral problems' but does not prevent a district from doing so

## What does the IDEA require

- Children with a disability receive, as appropriate, an FBA and BIP
  - When behavior is a manifestation of their disability
  - If the IEP team determines that they would be appropriate for the child
  - When the student's disciplinary change in placement would exceed 10 consecutive school days and the student's behavior was not a manifestation of his or her disability
  - When behavior impedes his or her learning or that of others, and the IEP Team decides that a FBA/BIP is appropriate

## So, is effective behavioral intervention dead post Hughes Bill?

- Still a basis for the use of FBA/BIP in many cases
- Discretion on the part of the IEP team, rather than mandate
- Some direction, but a lack of specificity as to how an assessment is done; how the plan is developed; or by whom
- No mandate for a behaviorally trained professional to spearhead the process

# The ethics of post-Hughes Bill intervention for the BCBA

- Best practices for a board certified behavior analyst may differ from district, state or federal policies or regulations
- Best practices become best practices only because of what those practices are

Changes in best practices can impact on the effectiveness of those practices, such that they are no longer best practices

# Why is the issue of how behavioral interventions are done so important

- Challenging behaviors are a primary cause of failures to acquire skills
- Challenging behaviors are a primary cause of failed placements/failed inclusion
- Challenging behaviors are a primary cause of failed transitions to adulthood
- Challenging behaviors place a significant burden upon parents, teachers and other caregivers

 The effective use of behavioral assessments and behavioral interventions for the replacement of challenging behaviors is science-based

- Long history of research
- Based upon a conceptual framework of learning theory
- Reliant upon the use of conceptually systematic techniques and data systems for evaluation and accountability
- It only works when it is done correctly, with fidelity, consistency and a reliance on data for decisionmaking

- When the process is legislated, compromised, modified, manipulated, or politicized, it is no longer the evidence-based science that we know can work so effectively with individuals with ASD.
- When steps are left out, it is not the same science
- When the assessors, developers or implementers are not well trained, well supervised or adequate to the job, it is not the same science
- Bad ABA is not just less effective ABA, it can be ineffective ABA

- An essential component of effective ABA is the relationship between functional behavioral assessment and the development of the behavior intervention plan; they are connected as two parts of the same process:
  - Behavioral intervention without assessment is not an appropriate standard of applied behavior analysis
  - Behavior plan development, which is not the direct result of functional assessment is not an appropriate standard of applied behavior analysis
  - Behavior plan change without reliance upon data is not an appropriate standard of applied behavior analysis

### Components of a Good Behavior Plan

- Assessment first
- Use the results of the assessment to understand why before you act
- Tie the strategies in the plan to the results of the assessment
- Understand the plan; commit to it; give it a chance
- Implement the plan correctly and consistently

# Factors in a successful behavior plan

- Regularly evaluate the quality of your reinforcers
- Be observant about the natural environmental consequences that maintain behavior especially yours
- Have a positive attitude
  - Accept your role
  - Stay calm and focused
  - Avoid blame
  - Believe that it will work

# What happens when we do behavioral intervention badly?

Behavior intervention plans fail more often than we like

Let's look at some of the reasons why ABA and behavior intervention plans fail

## System Issues

- We may work within nonbehavioral systems which may not see behavioral approaches as relevant
- In many systems, no behavioral expertise is available
- We don't acknowledge that every person or location can't provide effective behavioral intervention
- The people creating behavior intervention plans may not be adequately trained

## System Issues

- Exceeding the system skill level, the most difficult behaviors are often treated first
- Too often, the behavioral expert is not the one directly implementing or supervising the intervention
- We fail to adequately prepare the treatment environment for intervention
- Those that get the behavior plans don't use them

## System Issues

Those that are to implement the behavior plans do not trust or believe in the procedures

Those who are to implement the behavior plans don't believe that they are responsible; the student/child should be responsible for their own behavior change

#### Assessment Issues

We don't ask why behavior is happening before trying to change behavior

We don't consider how our behaviors affect the behaviors of others

We feel comfortable writing behavior intervention plans without prior assessment

#### Assessment Issues

We don't individualize our behavior plans

Behavior modification becomes a 'recipe' approach; the FAA becomes routine with no real connection to intervention

 Behavior plans without assessment often focus too heavily upon consequences rather than preventative antecedents

We remember to punish, but forget to reinforce

■ When we reinforce, we do it badly

We don't insure that our reinforcers are truly reinforcing

Even when we know the functions of challenging behavior, we don't act to make those behaviors

UnnecessaryInefficientIrrelevant

- Even when we use Functionally Equivalent Replacement Behaviors (FERB's), we don't insure that they are:
  - Truly functionally equivalent
  - As efficient as the challenging behaviors they replace
  - As effective as the challenging behaviors they replace
  - Under the spontaneous control of the consumer rather than the implementer

 We are not consistent in our implementation of behavior plans across individuals or settings

We give up too soon, allowing boredom or routine to erode maintenance efforts

According to one of the original behavior analysts, Richard Foxx, Ph.D., 10% of behavioral intervention is knowing what to do and 90% is getting people to do it. The Discrete Trial Model, as applied to those who you want to train to be interveners

- If 90% of good behavioral intervention is getting people to do what you want, then knowing how to modify the behavior of the interveners is more important than knowing how to modify the target behaviors of the student
- So...

# Get their attention

- Know whose attention you're trying to get
- Include the interveners in the development of the plan
- Listen to their concerns and fears
- Encourage their participation by explaining what's in it for them

#### Tell them what you want them to do

- Don't overwhelm the interveners with the assessment data; focus on what you want them specifically to do
- Give clear, simple and direct instructions, both about prevention and consequences
- Ask questions to insure that they are hearing the plan correctly

### Model and prompt as necessary to insure errorless learning

- Don't just drop the plan on your staff
- Model and demonstrate exactly what you want them to do
- Be available to brainstorm when the plan falters; don't let failure linger
- Build follow-up into the plan and plan for success

### Reinforce correct responding immediately and efficiently

- Intervene on those behaviors where you have the best chance for success
- Be there to encourage successful implementation
- Reward approximations, even if there's more work to be done; catch them being good
- Make sure your reinforcers are effective; if it doesn't make your staff's job easier, they're not likely to do it
- Be careful about extinction if you forget to continue to reinforce

# One more important reason why behavior plans fail

Durand has done extensive research on the failure of parents to benefit from behavioral training as interveners because of their own self-perception of powerlessness over the behavior of their children, and their belief that nothing that they try to do will be successful

He describes a model of intervention which he calls Optimistic Parenting, which combines the best of cognitive behavior therapy (CBT) and positive behavioral support (PBS)

# Optimism training

Durand described a process called 'Optimism Training' which improves the behavioral effectiveness of previously pessimistic parents

Interestingly, even pessimistic parents showed improvement in their children's behavior

 However, Durand attributed this to something he called the 'concession process' which involved getting better child behavior by giving in and avoiding confrontations, rather than teaching appropriate alternative skills The ethics of behavioral intervention in the current ASD environment

# What ethical challenges do we face in autism intervention

- Quality and quantity of BCBA's
- Reconciling the ethical guidelines of the BACB with the rules and regulations of the environments in which BCBA's must work
- Intrusion of external non-behavioral forces into the behavioral intervention process
- Role of commerce/money on the evidence-based implementation of ABA
- Dilution of the meaning of ABA
- □ Limitations of the one-on-one model over time
- Insuring successful transitions to adult services when do we start, how do we proceed, what happens when parents and professionals disagree

The strength of applied behavior analysis Applied behavior analysis is an elegant and robust science, because of • Unwavering adherence to long-standing scientific principles Clarity Precision Individualization Use of data to insure accountability

Our earliest 'ethical' standards were provided by Baer, Wolf and Risley (1968), who offered

Seven dimensions which served as our first practice guidelines

One of the strengths of our science is our continuing devotion to those seven dimensions

# A challenge that we face

- As we continue to grow as a field, and we
  - Develop larger and larger groups of providers
  - Strive to become the intervention standard for behavior change across populations
  - Move into more complex and diverse applied settings

We must maintain empirical purity, quality of intervention and credibility

## Two of our most significant ethical challenges

Those behavior analysts who continue to endorse or implement non-evidence based/nonbehavioral practices

Those behavior analysts who utilize evidencebased, behavioral practices in inadequate or incorrect ways  Both types of ethical lapses lead potentially to
 an unclear message as to what applied behavior analysis should be, and
 poor outcomes

Both serve to weaken the credibility of the field at a time when credibility is most essential

## The first ethical challenge" The issue of 'fad' interventions

- Widely discussed and addressed within the field
  - Multiple comprehensive presentations by Dr. James Todd
  - Multiple articles, including those of Dr. Zane, on our panel
  - The aggressive and vigilant efforts of the Association for Science in Autism Treatment

# The second ethical challenge

- The variety of potential influences upon the practice of applied behavior analysis in complex and diverse settings
  - and upon our continued adherence to the Seven Dimensions of Applied Behavior Analysis

This is less widely discussed and understood, but potentially more destructive than the first

#### Baer, Wolf and Risley, JABA, 1968

Baer et al, in introducing the Journal of Applied Behavior Analysis (JABA) in 1968, summarized the 7 essential dimensions that define applied behavior analysis:

- Applied
- Behavioral
- Analytic
- Technological
- Conceptual system
- Effective
- Generality

#### Baer, Wolf and Risley – JABA, 1968

In summary, Baer et al asserted that applied behavior analysis should make obvious:

- the importance of the behavior changed,
- its quantitative characteristics,
- <u>the experimental manipulations which analyze with</u> <u>clarity what was responsible for the change</u>,
- the technologically exact description of all procedures contributing to that change,
- the effectiveness of those procedures in making sufficient change for value, and
- the generality of the change

### Some aspects of the complex environment in which we now apply behavior analysis

- The intensity of external focus upon our technology
  - Broader dissemination of services to a growing ASD population
  - Increased media attention
  - Increased attention of legislative and advocacy groups
    - Potential misunderstanding, misrepresentation or misapplication of our behavioral jargon, our behavioral concepts and our behavioral interventions by nonbehavioral parties

### Some aspects of the complex environment in which we now apply behavior analysis

- A diverse and demanding customer base
  - Contradictory expectations
  - Unreasonable expectations
  - Unexpected or unwanted nonbehavioral collaborators in the assessment, intervention and data analysis processes
    - Multiple and, often subtle, impacts upon decision making which should be purely conceptual, empirical and data-based

### Some aspects of the complex environment in which we now apply behavior analysis

- The influences of commerce on the scientific processes that underlie applied behavior analysis
  - Some subtle and insidious
  - Some obvious, but unavoidable
  - Most unexamined to date
    - Impact on clinical decision making
    - Impact on collaboration
    - Impact on individualization
    - Impact on clarity and transparency
    - Impact on how we collect, interpret and present data, especially data on unsuccessful outcomes

#### In recent years, applied behavior analysis has developed a bit of a split personality

- Dr. Edward Morris (2009) identified at least five different meanings for the term 'ABA'
  - As a sub discipline of the field of behavior analysis, and within the arena of autism, this sub discipline encompasses at least four other meanings:
  - As applied and intervention research
  - As ABA interventions based on that research
  - As comprehensive programs of ABA interventions based on that research and those interventions
  - As Lovaas' comprehensive program of ABA interventions

#### The evolution of 'ABA'

- ABA has become a nickname or short cut, to describe, at best, a broad repertoire of behavioral interventions and, at worst, any set of interventions, when applied to individuals with ASD
- ABA has come to be seen as a technique of its' own, rather than the empirical process of data-based accountability across interventions, which has been the hallmark of applied behavior analysis
- ABA has become a kind of a brand name, as in 'ABA services', 'ABA programs' and 'ABA providers'

#### In the new world of ABA

Among those who provide behavioral services, it may be easy to understand the subtle differences that have evolved between applied behavior analysis, as a scientific process of databased behavioral accountability, and ABA, as an abbreviation for the range of behavioral intervention strategies used with individuals with autism

#### In the new world of ABA

However, it is not always clear that the general public, including those who often mandate, purchase or consume ABA services, understands or cares about the specific meaning of 'ABA', or the differences between applied behavior analysis, effective behavioral instruction, discrete trial training, ABA or even many other popular, but non-behavioral ASD interventions

#### In the new world of ABA

- Unfortunately, even those behavior analysts who strive diligently for scientific integrity may lose control of how the term 'ABA' is used or misused by others
- If this is true, this is potentially a very significant loss of control

#### The impact of 'customers'

- A demanding customer base and a unique political/legal environment for ASD can both lead at times to:
  - Decisions regarding the kind, quantity, direction, or duration of services, which may be mandated or defined by external, nonclinical entities, sometimes independent of or in direct contradiction with data-based assessments or outcomes

Sometimes, ABA providers are required, by the unique circumstances of individual cases, to allow others either to define their technology or to establish the parameters of assessment, intervention and evaluation of their results

When this happens, ABA providers can not always maintain adherence to the rigor and accountability upon which their behavioral technology should be based

ABA providers have not always known how to respond when their practices have been misunderstood, misinterpreted, or misapplied, even by their own customers

#### ABA as a business

- The business of ABA has tended to become more ambiguous and less specific, perceived by the public (for right or wrong) as a kind of all-purpose ASD panacea
- ABA, as a proprietary product, has become less transparent, less universal;
  - now that it has owners and competitors for market share, the details and processes of ABA have tended to become less public, less specific and less collaborative
- With ABA becoming a product, and ABA services becoming a competitive business, applied behavior analysts working in ASD have become 'ABA providers', a complex combination of scientist, clinician, marketer, entrepreneur and employer

#### In other words,

We are in the midst of the ongoing evolution from:

An experimental science to

An applied science to

A scientific/commercial endeavor across diverse and complex settings

#### OBM as the model of commercial applied behavior analysis

- OBM is a subdiscipline within applied behavior analysis which has demonstrated very successful integration of science and business
  - Clearer clients relationships
  - Clearer expectations
  - Direct relation between observed outcomes and continued service needs

#### ABA vs OBM

- Frequent disconnection between the funder and the client
- Often the funding is mandated by third parties, to be paid by customers who did not request or desire the service
- Less clear expectations with regard to outcomes
- Less direct relationship between the quality of outcomes and the continuation of services
- These make for a more complex commercial environment

- The applied dimension is satisfied
- ASD intervention is clearly of social relevance
- However, a concern is the extent to which, at times, the diagnosis of ASD alone has been allowed to become the rationale for intervention, without further individualized and data-based assessment and analysis
  - "I want the autism/ASD intervention"

The behavioral dimension is under some pressure in the world of ABA

While research-based ABA interventions remain true to the requirements of precise measurement and observer reliability, ABA practice in the marketplace is, at times, not as precise in the measurement of behavior and in the presentation and interpretation of data

- Commercial, competitive and external pressures can influence, even subtly, how data is collected, interpreted and presented; especially bad data, which generally is not good for future business
- Data is sometimes collected retrospectively, by memory, at the end of extended sessions
- Sometimes, data is not collected at all
- Observer reliability is often missing

The analytic dimension faces significant challenges

- If interventions are based upon diagnosis alone or are not individualized; or
- data collection is insufficient; or
- outcomes are determined or defined, not by data, but by the non-data based decisions of others; or
- data-based successes or failures do not determine future services delivery decisions; or
- the definitions of acquisition or mastery are unclear;
- then demonstrating responsibility for the occurrence or nonoccurrence of behavior is effectively impossible

An additional concern with regard to the analytic dimension is raised by Baer et al, when they write:

When behavioral procedures are complex and multifaceted, they 'clearly need to be analyzed into their effective components.' Most current commercial ABA programs are very complex, multi-component packages;
However, without specific empirical analysis of those components, or even general outcome data, there can be no real demonstration, either of the efficacy of those packages as a whole, or the relative efficacy of any single component or any combination of components

- The technological dimension can be corrupted when the need for specificity in the definition of techniques is preempted or compromised by the commercial need to maintain proprietary control over the product;
- or the economic/marketing need to have a unique, proprietary product that is different enough from one's competitors;
- or uncomplicated enough for nonscientific consumers;
- or general enough to be perceived as applicable to the broad spectrum of individuals, all of whom might carry the diagnosis of ASD

- Adherence to Conceptual behavioral systems can be held hostage to the need for marketing uniqueness and the tendency to rename and repackage techniques in order to maintain that uniqueness
- ABA providers may be faced with the challenge of making their techniques appear novel and interesting, while still maintaining clarity and adherence to a historical behavior analytic conceptual model
- The challenge in a competitive marketplace is, if we all have the same conceptual system as applied behavior analysts, how can any of us assert that our agency or approach is better? Yet the assertion is heard that, "My ABA is better than yours."

**Effectiveness** of ABA interventions for ASD has become a complex and elusive concept, for a number of reasons.

- If recovery from ASD is the anticipated outcome, when do we know when we are effective and how do we define effectiveness, short of recovery?
- Can we rely on measures of effectiveness based upon numbers of tasks 'mastered' when no published research uses that criteria in measuring the success of behavioral interventions for individuals with ASD?
- When the intensity, duration and makeup of our services is defined by others, at times independent of data or the quality of our results, how do we define and evaluate effectiveness?
- When services are part of a multi-component package, how do we know what part of our services have been effective?

- Effectiveness, as a concept, should be an empirical determination
- However, when there is no specific need to support treatment claims with new outcome data and no economic cost for the absence of such data, there may be no pressure to conduct outcome studies of the effectiveness of one's interventions;
- As a result, there are very few, empirically sound outcome studies from current ABA providers

- The issue of **generality** (or generalization) of outcomes is critical in evaluating the efficacy of all behavioral interventions, but it should be especially critical when we are marketing the enduring value of our services in an competitive environment
- However, the proprietary nature of ABA programs and the competitive marketplace often lead to a segregation of services and team members who can't or don't talk to each other about what they are each doing with the same child
- The lack of collaboration and information sharing, as well as the limits on the environments in which interventions occur, all make it harder for 'team members' to work together effectively and to transition services between settings; this can limit the successful generalization of results

### Individualization - an important dimension, not specifically addressed by Baer et al, 1968

- Individualization of intervention, a hallmark of applied behavior analysis, can become lost in the pressure to be accessible to a broad target audience and by the public need to perceive of ABA as a product appropriate to the needs of all individuals on the autism spectrum
- Commercial pressures to create universal treatment packages and one-size-fits-all recommendations can impact on the scientific need to insure that each behavioral intervention program is individualized to meet that unique child's needs



What is the danger if we fail to maintain the scientific rigor required by applied behavior analysis, possibly as a result of the unique commercial and political dynamics of autism intervention?

Without scientific rigor, ABA is not applied behavior analysis, it is not supported by the applied behavior analysis literature and it is no longer an evidence-based, best practice for individuals with ASD

- If we allow ourselves to be influenced by the money to be made...
- If we allow ourselves to become advocates, marketers or entrepreneurs first, and applied behavior analysts second...
- If we allow others to misapply our technology, misrepresent our technology, or 'borrow' our technology for nonscientific purposes...
- If we allow applied behavior analysis, as applied to ASD, to be different from applied behavior analysis as applied to everything else...

We run the risk of focusing so much on clinical delivery that we ignore the need to develop and enhance the science of applied behavior analysis

We run the risk of compromising the empirical accountability that has always made applied behavior analysis powerful and effective

We run the risk of losing control of our science to others who do not understand or respect its' legacy

#### So what should we do?

Commit ourselves to the scientific dimensions of applied behavior analysis whenever we offer ABA services

Be aware at all times of the influence of commerce on the clinical decisions that are made

Resist external decision makers who override data-based decision making We must continue to do research on what components of ABA are effective and why

- We must support new outcome studies rather than continuing to rely on decades-old ones
- As Ivar Lovaas has said, on his own Institute website:
  - *"If we lose or minimize the importance of peerreviewed outcome data, we abandon the defining feature of behavioral approaches to social problems."*

#### So what should we do?

Consider the essential need in all ABA programs for quality control, ethical policies, external review and long-term outcome studies

Develop collaborative work groups within each behavioral community to support and encourage conversation and collaboration between behavioral colleagues

#### So what should we do?

Create external review boards, though local ABA chapters, the national BACB or the national ABA, to develop standards for effective behavioral intervention

Make sure that, in addition to the focus of evidencebased interventions, we keep the focus on treatment integrity and the fidelity of the current applications of behavioral interventions with the research upon which those interventions are based



While it is important that we continue to educate the public regarding applied behavioral analysis/ABA as the most evidence-based intervention for individuals with ASD...

It is even more important that we realize that treatment integrity by behavior analysts within 'ABA' programs may be even more important to the long-term legacy of the science of applied behavior analysis

#### I would suggest that...

We are confident and skilled at the science of applied behavior analysis

We're getting better and better, as "ABA providers" at the commerce

However, to date, we have not always consistently integrated the two in an efficient, effective or ethical manner