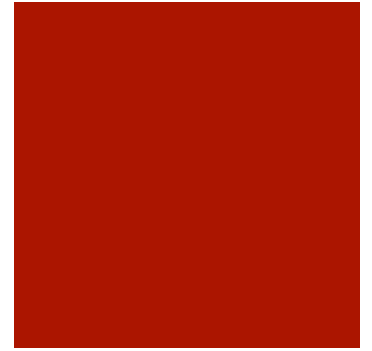




Autism: Local and National Updates

Jeffrey Okamoto M.D., FAAP and Chanel Kealoha, PsyD
April 16, 2016

Learning Objectives



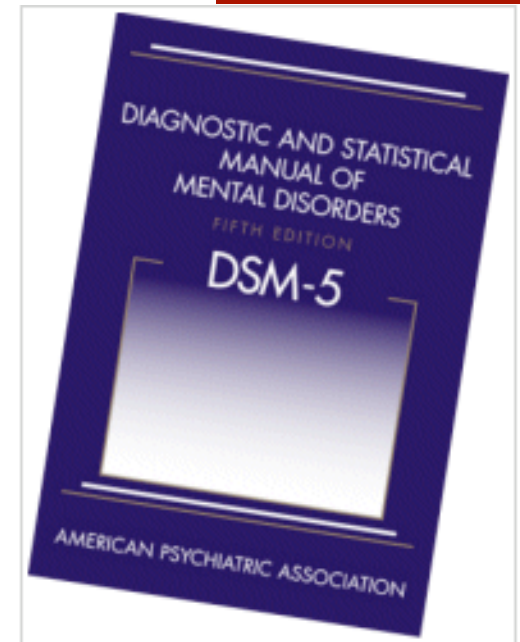
- 1. Utilize the DSM-5 criteria for autism spectrum disorder
- 2. Discriminate between autism screening and evaluation
- 3. Manage a child/teen with autism by using appropriate professionals
- 4. Use the new Hawaii laws and procedures to treat autism

DSM

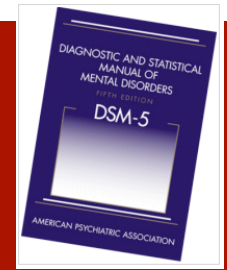
- The *Diagnostic and Statistical Manual of Mental Disorders* is one of the most important references for clinicians to make diagnoses
- Has mental health diagnoses, but also a variety of neurodevelopmental diagnoses
- No information about treatment
- Current version is the DSM-5
 - This changed from DSM-IV TR in May 2013

DSM-5

- “Autism Spectrum Disorders” has replaced “Pervasive Developmental Disorders”

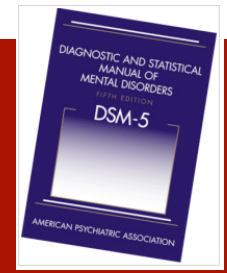


Important Change #1



- The new classification system eliminates the previously separate subcategories including Asperger syndrome, PDD-NOS, childhood disintegrative disorder and autistic disorder.
- All of these subcategories has been folded into the broad term autism spectrum disorder (ASD).

Important Change #2



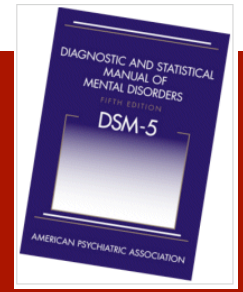
- Instead of three domains of autism symptoms (social impairment, language/communication impairment and repetitive/restricted behaviors), two categories are used:
 1. social communication impairment
 2. restricted interests/repetitive behaviors

DSM IV TR vs. DSM-5



- Under the DSM-IV TR: a person could qualify for a diagnosis of Autism by exhibiting at least six of twelve deficits in social interaction, communication or repetitive behaviors.
- Under the DSM-5: for an Autism Spectrum Disorder diagnosis requires a person to exhibit three deficits in social communication and at least two symptoms in the category of restricted range of activities/repetitive behaviors.

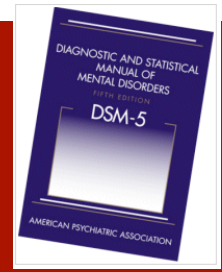
Important Change #3



- Within the “restricted range of activities/ repetitive behaviors” category, a new symptom is included:

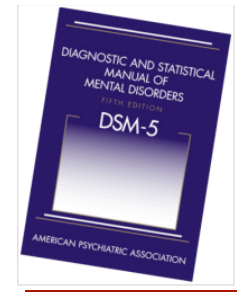
Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.

Important Change #4



- In addition to the diagnosis, each person evaluated is also described in terms of:
 - any known genetic cause (e.g. fragile X syndrome, Rett syndrome),
 - level of language and intellectual disability and
 - presence of medical conditions, such as seizures, anxiety, depression, and/or gastrointestinal (GI) problems.

Important Change #5



- A new category called Social Communication Disorder has been created. This will allow for a diagnosis of disability in social communication without the presence of repetitive behavior.

Prevalence – CDC Report

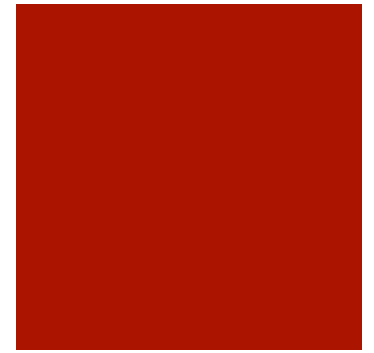


- March 28, 2014 Morbidity and Mortality Weekly Report (MMWR) reported 1 in 68 children have autism spectrum disorder

(This is an increase from 1 in 88 children from research done in 2008)

- 1 in 68 is based on research from 11 sites across the US in 2010 in the CDC Autism and Developmental Disabilities Monitoring Network
- 1 in 42 boys, and 1 in 189 girls in this latest report

CDC Report



- Dr. Colleen Boyle from the CDC National Center on Birth Defects and Developmental Disabilities believes that clinicians are better at diagnosing Autism Spectrum Disorders, especially those without intellectual disability
- This study relates 31% with intellectual disability IQ 70 or below, 23% considered borderline IQ 71 to 85, and 46% above 85 IQ in the sites that had data on IQ

Autism Screening



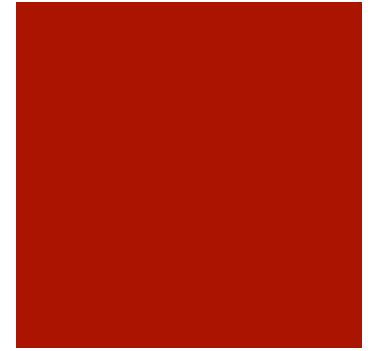
- How to screen a population of seemingly normal children?
- In addition to a general developmental screening tool, an autism-specific tool should be administered to all children at the 18-month or 24 month visit.
- Many of the primary care pediatricians are using the M-CHAT – the local chapter of the AAP endorses this

If Positive Screen on the M-CHAT

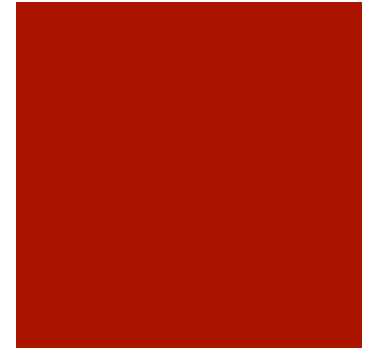


- Clinician can then see if the child/teen meets criteria using the DSM-5 criteria
- Screening can also lead to referral to specialist who makes definitive diagnosis
 - Psychologist
 - Developmental-Behavioral Pediatrician
 - Child Neurologist and/or Neurodevelopmental Disabilities subspecialist
 - Child Psychiatrist

Definitive Autism Diagnosis

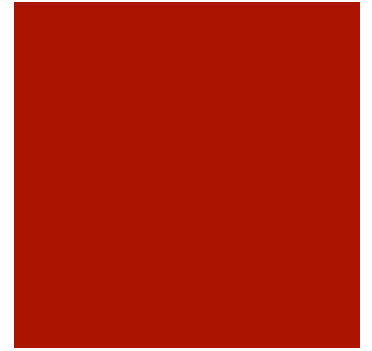


- This takes experience and training
- DSM-5 is the criteria
- The Autism Diagnostic Observation Schedule (ADOS) is the “gold standard” for the research world – many clinicians in Hawaii use this, especially in unclear situations
 - Need to have certification to do this
- Some clinicians uses standardized tools to interview family members
 - An example is the Childhood Autism Rating Scales (CARS)



Diagnosed with Autism
Spectrum Disorder, Now What?

Supports



- Behavioral
- Educational
 - Early Intervention and School Programs
- Complementary and Alternative Medicine
- Medications

Evidenced-Based Practices



- National Standards Project, Phase 2 (NSP2)
 - www.nationalautismcenter.org
(Free PDF report available for download)

- Identified interventions for individuals diagnosed with ASD at various ages that are:
 - Established Interventions
 - Emerging Interventions
 - Unestablished Interventions

Examples of NSP2 Identified Evidenced-Based Practices



- Behavioral Interventions (**largest category*)
- Language Training
- Modeling
- Parent Training
- Schedules
- Scripting
- Social Skills
- Story-Based Interventions (i.e., Social Stories)

Examples of NSP2 Identified Emerging Practices

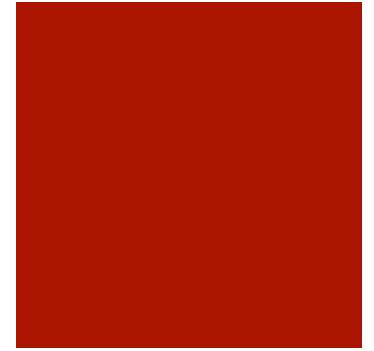


- Augmentative & Alternative Communication Devices
- Exercise
- Massage Therapy
- Music Therapy
- Picture Exchange Communication System (PECS)
- Theory of Mind Training

Recommendations for Interventions Selection

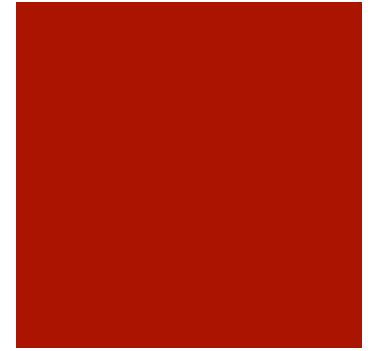


- Research findings are not the sole factor to consider when selecting an intervention
 - Consider the effectiveness of the intervention on the individual
 - Data! Data! Data!
 - What are the unique strengths, limitations, and needs of the individual?
 - Are there cultural, familial, and community factors to consider?



But What is ABA and PBS?

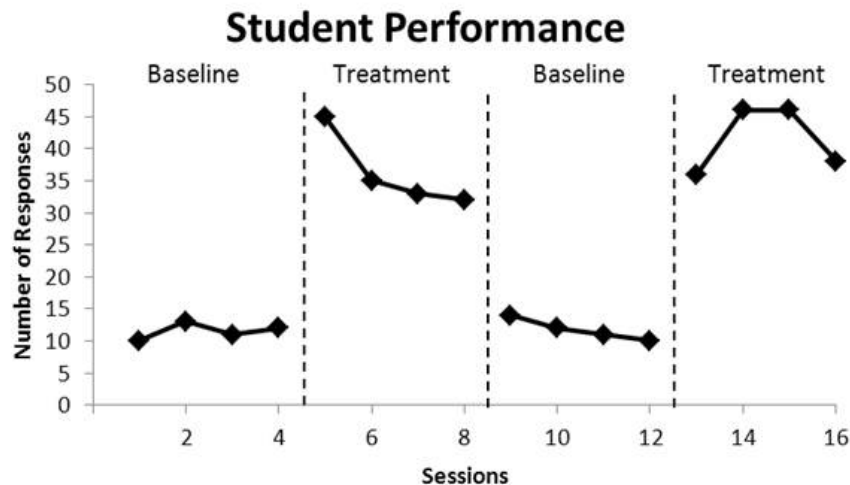
Applied Behavior Analysis



- Applied Behavior Analysis (ABA) is a scientifically validated approach to understanding behavior and has been demonstrated to produce improvements in communication, social relationships, play, self-care, and academic skills.
- American Academy of Pediatrics
“The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.”

Applied Behavior Analysis

- Scientific approach aimed at producing socially significant behavior changes in a systematic and measurable way that is meaningful
- ABA includes the use of direct observation, measurement, and functional analysis of the relations between environment and behavior



Goals of the Treatment for Autism



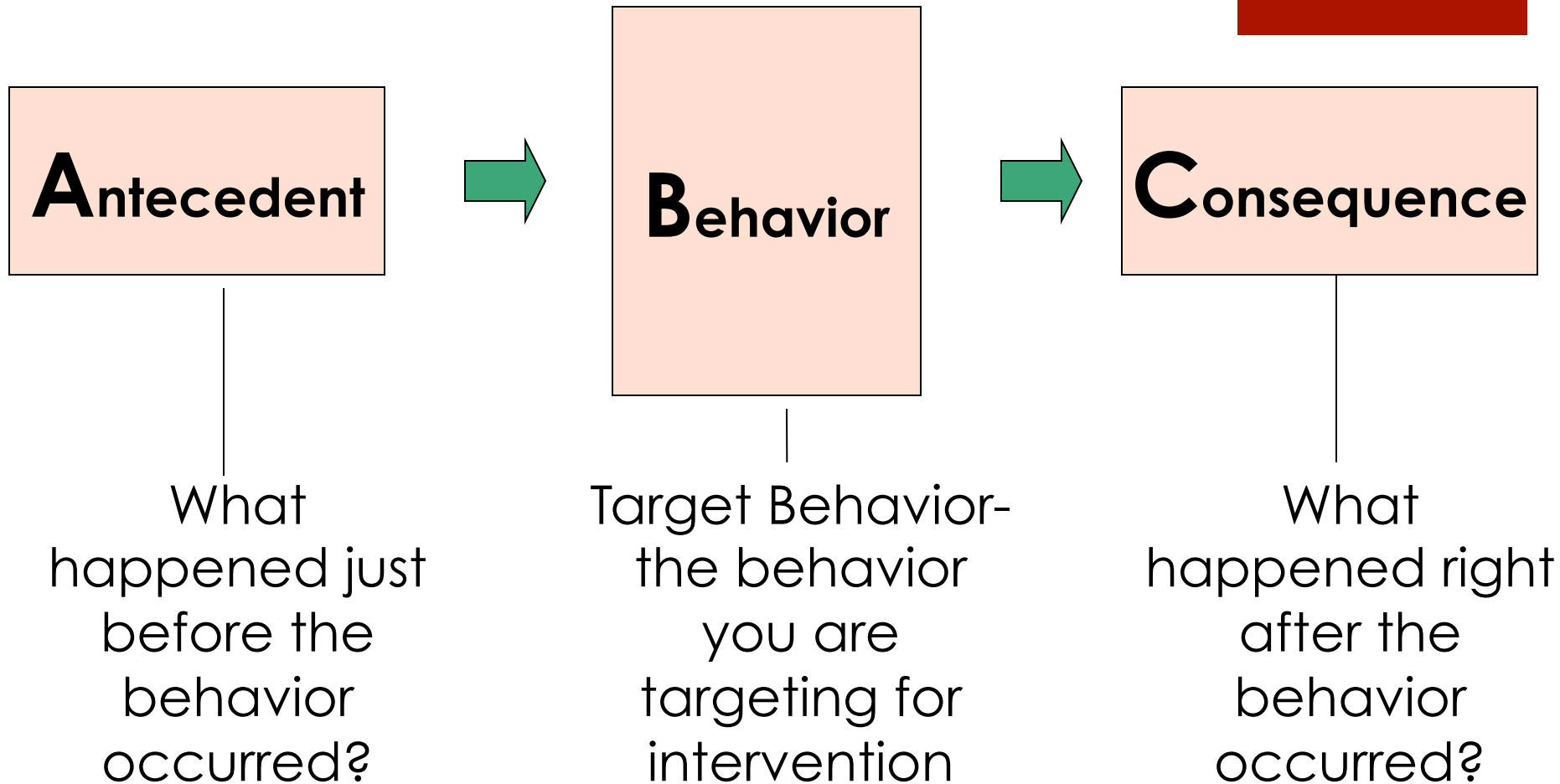
- Increase of appropriate verbal and nonverbal communication in home, school and work settings → Increase in IQ
- Social connectedness and interactions → Improvements in adaptive functioning (activities in daily living)
- Decrease or absence of stereotypical or unusual behaviors → Improvements in behavioral functioning
- Cessation of aggressive or disruptive behaviors (such as turning on and off lights) →

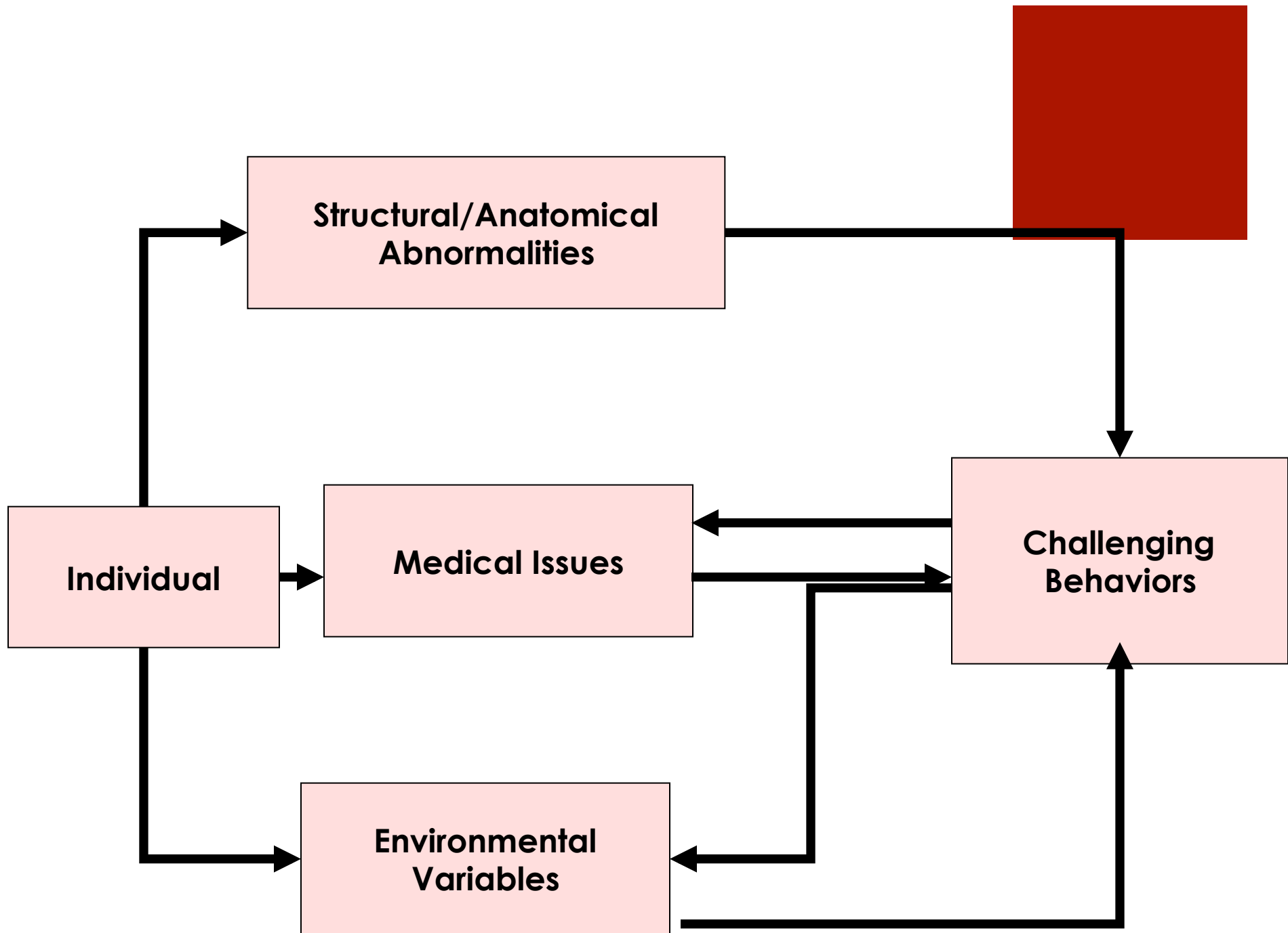
ABA Practices



- Comprehensive Assessment
- Understanding the context in which the behavior occurs
- Carefully constructed, individualized and detailed behavior-analytic plan treatment plan
- Consistent, on-going objective assessment and data analysis to inform clinical-decision making

Functional Behavioral Assessment



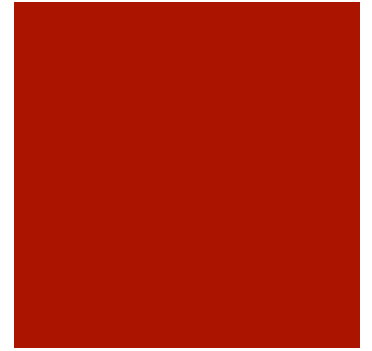


Generating a Plan



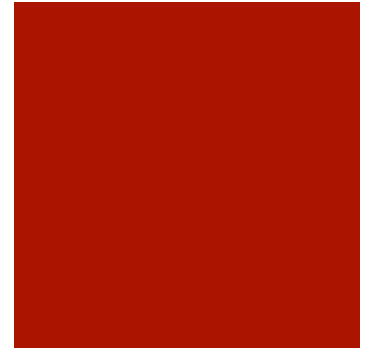
- Developing a profile of the person's strengths and needs
 - Who is _____?
 - What are _____'s strengths (e.g., capacities, interests)?
 - What are _____'s challenges and needs?
- Identifying the circle of supports who will be involved in plan
- Targeting specific settings and situations that require intervention
 - How does the plan align with the goals of the person?
 - Do the people implementing the plan have the capacity & commitment to do so?
 - Are the resources needed for the plan available?

Monitoring Outcomes



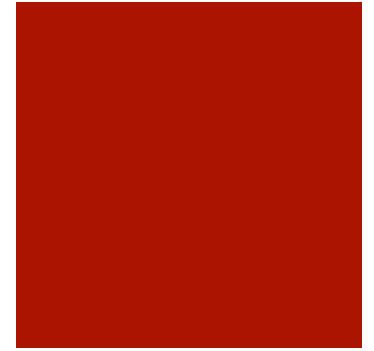
- Track changes in the person's target behaviors and evaluate broader lifestyle changes that occur as a result of the intervention
- Use objective measures to document success
- If minimal progress occurs in decreasing target behaviors, increasing replacement skills, or enhancing the person's lifestyle, **the plan should be reevaluated** (*Data! Data! Data!*)

Location Where Treatment Is Delivered



- Home
- Community
- School
- Outpatient/Clinic
- Inpatient

Who can provide ABA?



- Registered Behavioral Technician (RBT): 132
- Board Certified Assistant Behavior Analyst (BCaBA): 16
- Board Certified Behavior Analyst (BCBA): 99
- Board Certified Behavior Analyst Doctoral Level (BCBA-D): 6

Positive Behavior Support



- Positive Behavior Support (PBS) is a process for resolving challenging behaviors by understanding the relationships between a person's behavior and aspects of his or her environment. It offers strategies to modify the environment in order to prevent the occurrence of these behaviors; teaches skills to replace challenging behaviors; outlines responses to challenging behaviors to reduce the likelihood that these behaviors will reoccur in the future; and offers proactive and functional strategies to promote a positive lifestyle change.
- PBS includes a foundation in person-centered values, a commitment to outcomes that are meaningful, and services tailored to an individual's unique interests and strengths.

Positive Behavior Support



- Goals of Positive Behavior Support (PBS):

To support people with disabilities to:

1. Enjoy life
2. Be as independent as possible
3. Live a normal life
4. Overcome problem behavior

- Utilizes the ABC Model

PBS Practices



- Defining the behavior (observable, measurable)
- Identifying the ABCs
 - Functional Assessments of Behavior
 - Targeting Consequences: Reinforcement & Punishment
- Teaching Functional Skills
 - Modeling
 - Prompting

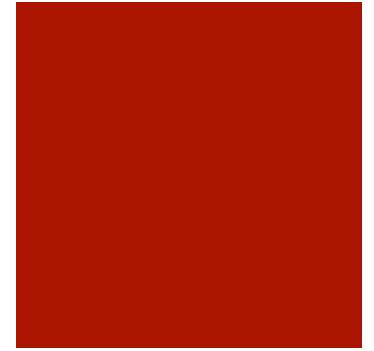
Location Where PBS Is Delivered



- Home
- Community
- School
- Outpatient/Clinic
- Inpatient

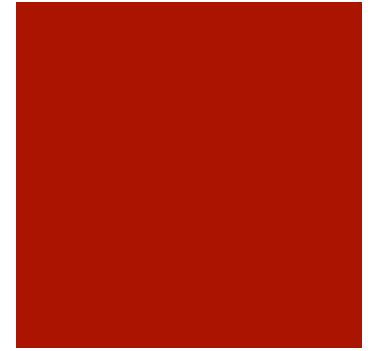
Who can provide PBS?





Similarities Between the Evidenced-Based Practices, ABA, and PBS?

Services Mandated by IDEA

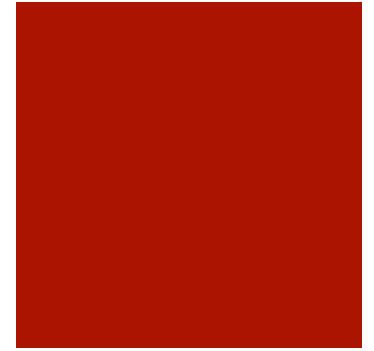


- Early Intervention services (in Hawaii - Department of Health: H-KISS)
- Special Education services

Both of the above can provide

- Skills trainers, Speech-Language therapists, Special Educators, Occupational Therapists, Autism consultants
- ABA, Sensory integrative approaches

Complementary and Alternative Medicine (CAM)



- Autism is a chronic condition
- Many beliefs on causes/etiology of autism
- Many proposed treatments, some advocated by professionals including physicians, naturopaths, and therapists
- Many of these treatments have anecdotal evidence, some have poor results in clinical studies, some have not been studied yet

	Total (n = 74)	
	No.	(%)
Diet/Supplements		
Gluten-free	39	(52.7)
Essential fatty acids	38	(51.4)
Casein-free	37	(50.0)
Probiotics	36	(48.6)
Digestive enzymes	27	(36.5)
Carnitine	10	(13.5)
Biological treatment		
Antifungal	30	(40.5)
Melatonin	16	(21.6)
Homeopathy	12	(16.2)
Antibiotics	7	(9.5)
Secretin	7	(9.5)
Chelation	6	(8.1)
Other CAM therapy		
Sensory integration	37	(50.0)
Chiropractor	16	(21.6)
Delay vaccinations	15	(20.3)
No vaccinations	15	(20.3)
Hippotherapy	13	(17.6)
Massage	11	(14.9)
None	4	(0.5)

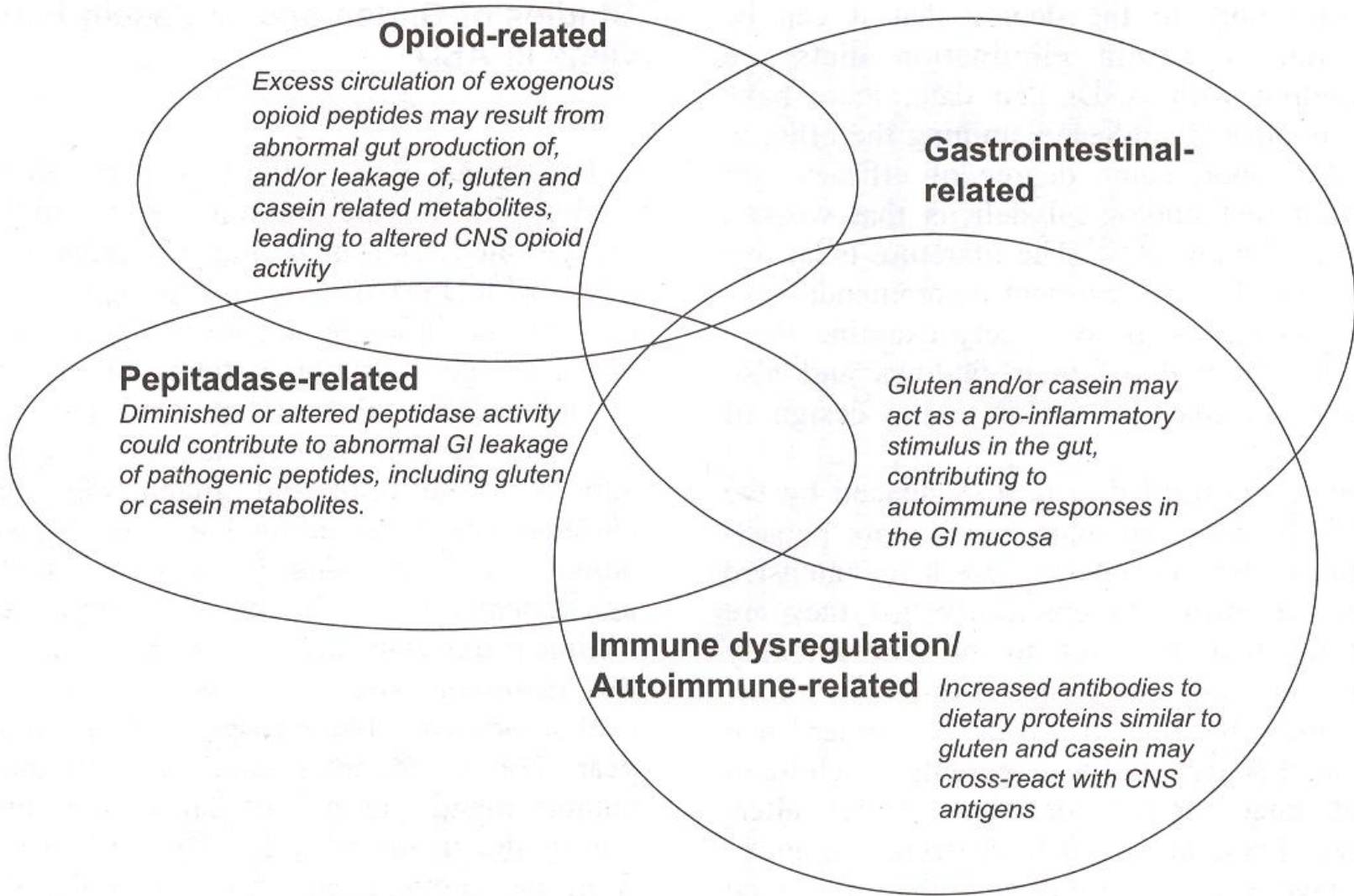
CAM indicates complementary and alternative medicine;

Why Diets and GI Treatments?



- Co-occurrence of significant GI symptoms in children with autism
- 25% have chronic diarrhea and 25% have chronic constipation, more than siblings or unrelated controls
 - (Melmed et al. Journal of Pediatric Gastroenterology and Nutrition 31 [Suppl 2], S31)

Elimination Diets in Autism Spectrum Disorders



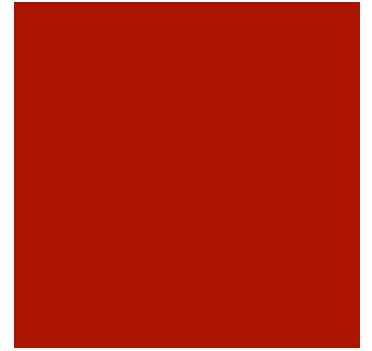
Gluten and Casein Free Diets (GFCF)



- Studies funded by NIH did not show efficacy in blinded situations

Secretin

- Double-blind, placebo controlled trials of this intestinal hormone failed to demonstrate significant improvement in behaviors

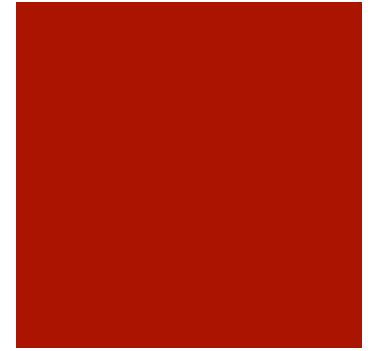


CAM Summary



- Individuals on these regimens need to be followed closely with appropriate expectations regarding the treatment - look at specific target behaviors
- Families need to be told of the critical importance of concomitant behavioral and developmental interventions
- Families should avoid undue financial burdens

Medications



- Purpose of medication needs to be clear
- There is a paucity of well-designed randomized clinical trials in children and adolescents with autism

Table 23.1-3. Common symptoms of distress expressed by individuals with autism

Self-injurious behaviors including head banging

Aggressive behaviors

Agitation

Self-stimulatory behaviors

Sleep disorders (e.g., increased difficulty in going to sleep, more frequent nighttime wakening)

Regression and loss of skills

Regression in toilet training

Behavior regression

Masturbation

Poor attention and increased distractibility and hyperactivity

Rectal digging and fecal smearing

Excessive eating

Weight gain or weight loss

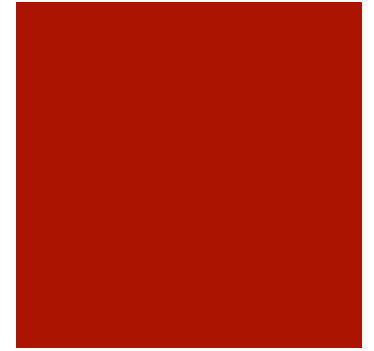
Increase in toe walking

Table 23.1-2. Potential side effects of medications in individuals with autism

Medication class	Potential side effects
Decongestants	Agitation
Antihistamines	Sedation, disinhibition
Anticonvulsants	Irritability, activation, drowsiness, dizziness, personality changes, clumsiness, nystagmus, gingival hypertrophy, rash, hirsutism, alopecia, diplopia, confusion, dyspepsia, photophobia, hyperphagia
Stimulants and nonstimulants	Agitation, aggressiveness, stereotypies, tics, isolatory behaviors, loss of appetite, nausea, lethargy
Mood stabilizers, neuroleptics	Tremor, weakness, posturing, dyskinesias, autonomic movements, agitation, weight gain
Serotonin reuptake inhibitors	Agitation, hyperactivity, sleep disruption, constipation, weight gain, constipation

Some Hawaii Stuff





Luke's Law

- This year, Governor David Ige signed the autism insurance reform bill, making Hawaii the 42nd state to require certain health insurance plans to cover treatment for autism spectrum disorders
- This requires state-regulated insurance plans to cover medically necessary treatment for autism, including behavioral health treatment, psychiatric, psychological, pharmaceutical and therapeutic care. This requires plans to cover applied behavior analysis with a maximum of \$25,000 up until age 14

EPSDT Covers Autism Treatment!



- Many states, including Hawaii were being sued for not providing, for children with autism, the T in EPSDT
- No state has ever won a lawsuit around this
- The Centers for Medicare and Medicaid Services (CMS) came out with a guidance recommending treatments in autism for patients that have EPSDT. This requires coverage of applied behavior analysis up until age 21

In Other Local News



- Governor Ige also signed the Hawaii ABLE savings program act, which allows families the opportunity to set up tax-exempt 529A savings accounts for disability-related expenses
 - This allows ABLE account funds to be disregarded for means-tested federal programs such as SSI and Medicaid, which caps (usually at \$2000) the amount an individual with a disability can save
- Also a law was passed to require licensure of behavior analysts and funds the implementation of a Behavior Analyst board

Summary – Autism Spectrum Disorders



- DSM-5 criteria is active
- Prevalence is high – CDC relates 1 in 68
- M-CHAT is a good screen at 18 and 24 months of age
- There are evidenced-based practices for treatment of ASD
- Risperadone FDA approved, but watch use of any medication that is used for behavior
- Early Intervention and School are important supports to refer to
- New Hawaii law and procedures for insurance coverage of autism treatment



And Just as Important as all of
That Was, Don't Forget About...
YOU!

Caring for the Caregiver



- Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself!
 - Ask for help
 - Is there someone who can: Cook for you? Run an errand? Do a load of laundry?
 - Talk to someone
 - Friends, Family; Parent Support Groups; Advocacy Groups
 - ASD community events
 - Individual, Couples, or Family Therapy

(adjusting to & accepting the diagnosis; transitions; feelings of isolation/inadequacy/confusion)
 - Do pleasurable activities (**scheduled, if needed*)
 - Maintaining relationships with spouse, other children, friends, family
 - REST!
 - Get going! Getting treatment started will help

Resources



- The Organization for Autism Research
- Association for Science in Autism Treatment
- Autism Speaks
- Behavior Analyst Certification Board (BACB):
<http://bacb.com/>
- National Standards Project, Phase 2 (NSP2):
www.nationalautismcenter.org
- Positive Behavior Support Training Curriculum

Local Resources

- Center for Disability Studies: <http://www.cds.hawaii.edu>
- Autism Society of Hawaii: <http://www.autismhawaii.org>
- Special Parent Information Network:
<http://www.spinhawaii.org>
- Hawaii Association for Behavior Analysis: www.hawaiiaba.org