

Autism Basics

National Autism Conference
State College, PA
August 2nd, 2011

Elizabeth Maher
PaTTAN Autism Initiative



Pennsylvania Training and Technical Assistance Network

PaTTAN's Mission

The mission of the Pennsylvania Training and Technical Assistance Network (PaTTAN) is to support the efforts and initiatives of the Bureau of Special Education, and to build the capacity of local educational agencies to serve students who receive special education services.

PDE's Commitment to Least Restrictive Environment (LRE)

Our goal for each child is to ensure Individualized Education Program (IEP) teams begin with the general education setting with the use of Supplementary Aids and Services before considering a more restrictive environment.

So what does my resident autism guru have to say about Autism?





Objectives:

- Acknowledge the diversity of individuals diagnosed with Autism Spectrum Disorders (ASD)
- Become familiar with process of diagnosis
- Recognize common characteristics and myths of ASD
- Review evidence base for education and intervention options
- Discuss issues related to special education regulations including IEP/FAPE/LRE

Faces of Autism: Matthew



What is Autism? How do Sarah and Matthew both fall on the Autism Spectrum?

- Autism is a complex developmental disability that typically appears during the first three years of life.
- By definition ASD is present at birth or very early in development (prior to age 3 years)
- It is one of the 5 disorders under the umbrella of “Pervasive Developmental Disorders”:
 - Autism
 - Asperger’s
 - PDD-NOS
 - Rett’s Syndrome
 - Childhood Disintegrative Disorder

Autism Continued....

- Affects essential human behaviors such as social interaction, communication, and establishing relationships
- Has life long effects on learning, interacting with others, becoming independent, and participating in the community

National Research Council, 2001

Autism Continued....

- Varies in severity of symptoms, age of onset, and association with other disorders
- Manifestations vary across children and within an individual over time
- Many combinations of possible symptoms
- No single behavior that is always typical or present in every individual

National Research Council, 2001

Diagnostic Criteria for Autistic Disorder

1. Qualitative differences in reciprocal social interaction
2. Qualitative differences in communication
3. Restricted repertoire of activities & interests

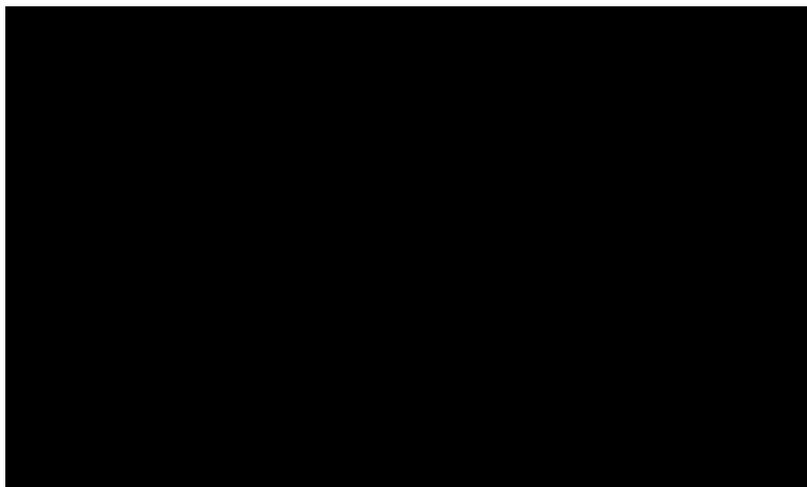
(The Diagnostic and Statistical Manual of the American Psychiatric Association is the primary source of Diagnostic Criteria for ASD. Commonly referred to as DSM)

I. Qualitative impairment of reciprocal social interaction

- Impairment in use of multiple nonverbal behaviors including poor eye contact or lack of eye contact
- Lack of developmentally appropriate peer relationships
- Lack of spontaneous seeking to share enjoyment, interests, achievements
- Lack of social or emotional reciprocity

2. Qualitative impairments of communication

- Delay or total lack of development of spoken language
- Impairment in ability to initiate or sustain conversation
- Stereotypic, repetitive, or idiosyncratic use of language
- Lack of appropriate levels of make-believe or social imitative play:



3. Restricted repertoire of activities & interests

- Preoccupation with stereotypic, restricted patterns of interest
- Inflexible adherence to specific non-functional routines or rituals
- Stereotypic and repetitive motor mannerisms
- Persistent preoccupation with parts of objects

Pervasive Developmental Disorder-Not Otherwise Specified

- Diagnosis criteria of autism not met.
- Some characteristics are evident.
- May be later diagnosed as autistic disorder

Aspergers Disorder

- Differs from Autism due to the absence of language delays
- Average to above average intelligence
- Impairment of non-verbal communication (facial and gestural expressions)
- Idiosyncrasies in verbal communication
- Usually want to fit in and interact
- Problem behavior
- Absence of intuitive understanding of others' affective communication

The 2 other disorders under the umbrella of ASD

Rett's Disorder:

- Progressive neurological disorder; MECP2 Gene ;affects only females
- Normal infant development then loss of skills
- Deceleration in head growth and severe behaviors without apparent function

Childhood Disintegrative Disorder:

- Apparent normal development for at least the first 2 years
- Loss of previously acquired skills in at least two of the following areas: language, social skills or adaptive behavior, bowel/bladder control, play, motor skills

Co-morbidity

- Fragile X
- Landau-Kleffner Syndrome
- Tuberous Sclerosis:
- Other seizure disorders
- Mental retardation
- Social Phobias
- Obsessive Compulsive Disorder
- Schizophrenia
- Speech and Language Disorders
- Aphasia
- Down's Syndrome
- Sensory Impairments
- Reactive Attachment Disorder

The Importance of Autism Diagnosis for families

- to help in understanding why the child does what he or she does
- to guide eligibility for services
- to guide intervention decisions
- to access sources of information

How is Autism Diagnosed?

- Autism can not be diagnosed through blood tests or brain scans
- Diagnosis made primarily through observation of a child's behavior.
- May be diagnosed by physicians including psychiatrist and licensed psychologist.

National Institute of Child Health and Human Development (NICHD):

Red Flags:

1. Does not babble or coo by 12 months
2. Does not gesture by 12 months
3. Does not say single words by 16 months
4. Does not say 2 word phrases by 24 months
5. Any loss of language or social skill

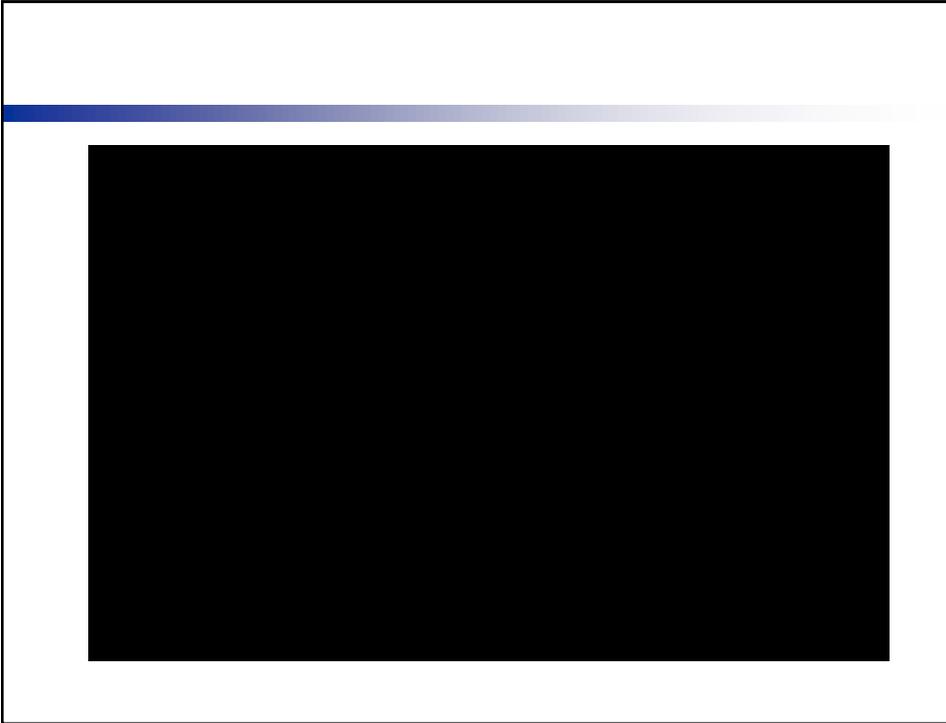
Diagnosis usually occurs around two years of age:
the time when differences in social communication and play skills may be more evident.

Generally, the earlier the diagnosis, the earlier intervention can begin.

Early intervention leads to better outcomes.

Diagnostic Methods

- Diagnostic decision making for Autism Spectrum Disorders is not always a one-time procedure; it is a complex process.
- Process can include:
 - Interview
 - Office observation
 - Specific checklists
 - Structured Observations
 - Record review (i.e. birthday party videos) – 



Diagnostic Methods: Examples

Diagnostic and screening tools that are commonly used include:

- Childhood Autism Rating Scale (CARS)
- Checklist for Autism in Toddlers(CHAT)
- Autism Screening Questionnaire (ASQ)
- The Gilliam Autism Rating Scale (GARS).
- The Autism Diagnostic Observation Schedule (ADOS) **

So one thing to remember is.....

As Dr. Peter Gerhardt says:

“If you’ve met one person with
autism.....you’ve met one person with
autism!”

Faces of Autism: Brendan

Review of Common Characteristics

Individuals with autism exhibit some of the following traits:

- Insistence on sameness
- Difficulty communicating
- Repetitive words or phrases
- Exaggerated, unexplained emotions
- Preference for “aloneness”
- Tantrums
- Difficulty interacting
- Little or no eye contact
- Irregular sleep patterns
- Engagement in perseverations
- Difficulty generalizing skills

Review of Common Characteristics

- Unresponsive to traditional teaching methods
- Sustained odd play
- Over/under-sensitivity to environmental stimuli
- No fear/danger awareness
- Extreme fear
- Over/under-activity
- Uneven gross/fine motor skills
- Non-responsive to verbal cues
- Odd eating habits
- Inappropriate attachment to objects 



Common Myths:

- Individuals with autism never make eye contact; they do not look at you
- Autism is a mental illness.
- Progress means a person doesn't have autism
- Individuals with autism don't speak.
- Autism can be outgrown.
- Individuals with autism can't learn.
- Underneath all the difficult behaviors is a normal person.

Common Myths

- Individuals with autism cannot show affection and do not respond to physical affection.
- Individuals with autism are very manipulative.
- Individuals with autism could talk if they wanted to.
- Individuals with autism do not want friends. 

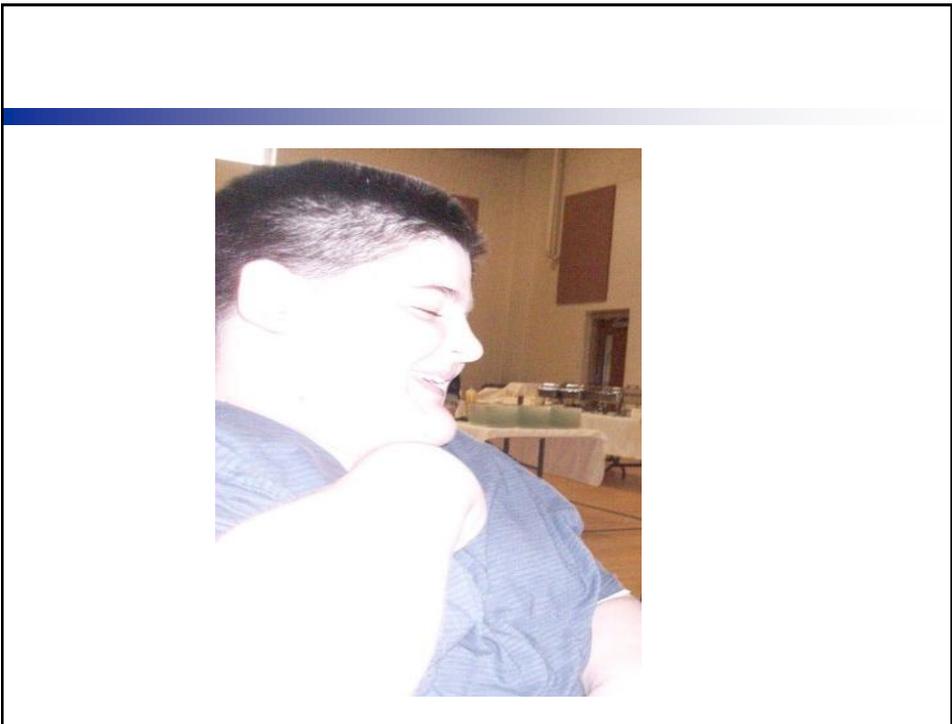
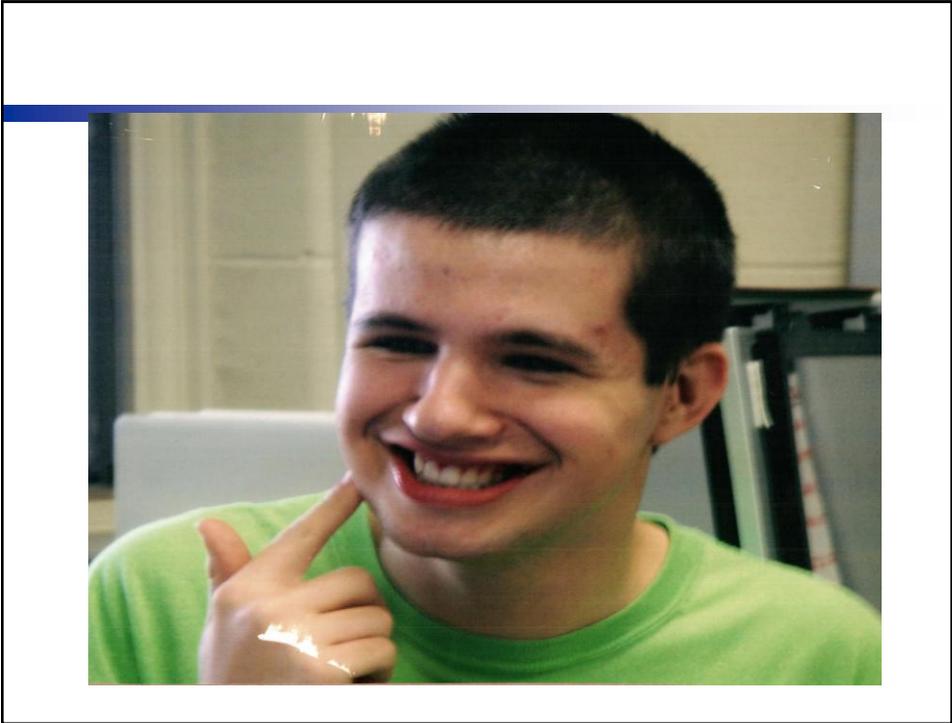


Common Myths

- Individuals with autism do not relate to peers/adults.
- Alexander manding from friend video

Common Myths

- Individuals with autism don't notice others and don't pick up cues from adults.
- When a person with autism does not respond to a question/direction to which he has shown a previous correct response, he is being stubborn/non-compliant/obnoxious.
- Individuals with autism can't smile. 



Causes

- No specific causes yet identified
- Current research links autism to biological or neurological differences in the brain
- Autism is believed to have a genetic basis, although no single gene has been directly linked to behaviors observed.
- Researchers are using advanced brain-imaging technology to examine environmental factors that may contribute to the development of behaviors related to the disorder.

National Autism Center

Beware “cause” versus “correlation”!

A correlation between two events does not mean that one *causes* the other

Celberti (2011)

Eg: correlation between ice-cream sales and playground accidents.....stop eating icecream!

So now what?

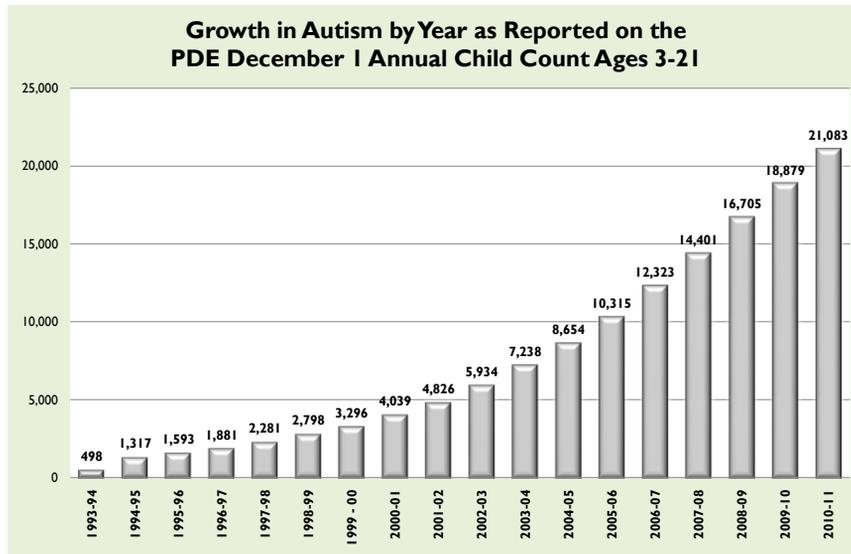
- If behaviors have an environmental basis, then we can manipulate the environment to change the behaviors!
- We can make a difference!
- No matter what the cause of the disorder, it is imperative we use evidence based interventions to make that difference

Choosing Interventions

- Approximately one in every 110 children has an ASD [CDC, 2009] 
- As the number of children diagnosed with ASD continues to skyrocket, so do the number of treatment options.
- Families, educators, and service providers must sift through a massive amount of confusing and often conflicting information about the myriad treatments available

National Autism Center Standards Report

In Pennsylvania alone....



Treatment option difficulties

- Treatment selection complicated by
 - uncertainty about the level of research supporting different treatments
 - evidence of effectiveness

National Autism Center Standards Report

Importance of Effective Treatments

- Societal costs for each individual with ASD across the lifespan is estimated at 3.2 million dollars (Ganz, 2007)
- With EFFECTIVE treatment the life-time costs can be reduced by 65% (Jarbrink & Knapp, 2001)

Determination of Effectiveness:

- look at research in terms of:
 - **Specificity to the ASD community**
 - **Quantity**
 - **Quality**
 - **Consistency**

National Autism Center Standards Report

National Standards Report (2009)

- A thorough review of the educational and behavioral treatment literature published between 1957 and fall of 2007
- Literature targeted the core characteristics and associated symptoms of ASD
- Treatment effectiveness based on
 - age
 - diagnostic groups
 - treatment targets.

National Standards Report

- Grouped the available treatments for ASD into 1 of 4 groups:
 - Established Treatments
 - Emerging Treatments
 - Unestablished Treatments
 - Aversive Treatments

II Established Treatments:

- Antecedent Package (*99)
 - Behavioral Package (*231)
 - Comprehensive Behavioral Treatment for Young Children (*22)
 - Joint Attention Intervention (*6)
 - Modeling (*50)
 - Naturalistic Teaching Strategies (*32)
 - Peer Training Package (*33)
 - Pivotal Response Treatment (*14)
 - Schedules (*12)
 - Self-management (*21)
 - Story-based Intervention Package (*21)
- * Number of studies.

Treatments based on ABA

- Approximately two-thirds of the Established Treatments were developed **exclusively** from the behavioral literature (e.g., **applied behavior analysis**).
- Of the remaining one-third of the Established treatments for which research support comes **predominantly** from the behavioral literature.
- This pattern of findings suggests that treatments from the behavioral literature have the strongest research support at this time

Applied Behavior Analysis

- A scientific approach to behavior
- Focuses on environmental events that are crucial to the understanding of behavior
- Its principles are used to change and improve behaviors
- Many experimental studies confirm the effectiveness of these principles
- These principles can be applied in a variety of settings with different types of people—infants to adults.

Using ABA to Educate Students in Inclusive Education
[PaTTAN 2009]

Unestablished Treatments

- Academic Interventions [10 studies]
- Auditory Integration Training [3 studies]
- Facilitated Communication [5 studies]
- Gluten- and Casein-Free Diet [2 studies]
- Sensory Integrative Package [7 studies]

Beware the Media and Internet!

- “There is a need to differentiate effective treatments that are scientifically validated from the plethora of “therapies” and “cures” lacking scientific support”

Celiberti, PhD, BCBA (2011)

- Research vs. the “next big thing” sensationalized by the media

“Googling” Autism Treatments:

The screenshot shows a Google search for "autism treatments" with approximately 10,200,000 results. The search bar includes the Google logo, the search term, and a search button. Below the search bar, there are navigation options for Everything, Images, Videos, News, and Shopping. The search results are listed on the right side of the page, including:

- Treatment For Autism - Find Out About Hyperbaric Therapy** (www.hbtusa.com) - Contact Us Today for Consultation
- Autistic Disorder Symptom** (www.autisticdisorderinfo.com) - Treat Irritability Associated With Autistic Disorder In Patients 6-17.
- Treatments for Autism | KylesTreeHouse.org** (www.kylestreehouse.org) - Educate yourself about choices with our online resources and more!
- Treatment - Autism Speaks** (www.autismspeaks.org/what-autism/treatment - Cached) - Treatment for autism is a very intensive, comprehensive undertaking that involves the child's entire family and a team of professionals. ... Treatment for the Core Symptoms of ... - Applied Behavior Analysis (ABA)
- Autism Treatments -- Therapies, Medications, and Alternatives** (www.webmd.com/brain/autism/autism-treatment-overview - Cached) - Apr 12, 2010 -- WebMD provides in-depth autism treatment information including behavioral therapy, speech therapy, medications, physical therapy, ...

On the left side of the search results, there are filters for location (Scranton, PA) and time range (Any time, Past hour, Past 24 hours, Past week, Past month, Past 2 months, Past year, Custom range...).

Checklist of things to look for when reviewing the research :

- Needs to be empirical – based on experiments
- Needs to have been scrutinized by scientists in the field
- Results need to be measurable and objective
- Research should be able to be reproduced

Let's try it out:



[Home](#) [About HBOT](#) [Treated Conditions](#) [Research](#) [Athletics](#) [Related Articles](#) [T](#)

Research

^ Autism

[Hyperbaric treatment for children with autism: a multicenter, randomized, double-blind, controlled trial](#)

[Hyperbaric oxygen therapy in Thai autistic children](#)

[Hyperbaric oxygen therapy might improve certain pathophysiological findings in autism](#)

[Hyperbaric oxygen therapy may improve symptoms in autistic children](#)

NCBI Resources How To

PubMed.gov
U.S. National Library of Medicine
National Institutes of Health

Search: PubMed Limits Advanced search Help

Search Clear

Display Settings: Abstract Send to: ?

BMC Pediatr, 2009 Mar 13;9:21.

Hyperbaric treatment for children with autism: a multicenter, randomized, double-blind, controlled trial.

Rossignol DA, Rossignol LW, Smith S, Schneider C, Logeurgist S, Usman A, Neubrandner J, Madren EM, Hintz G, Grushkin B, Mumper EA.
International Child Development Resource Center, Melbourne, FL, USA. rossignolmd@gmail.com

Abstract

BACKGROUND: Several uncontrolled studies of hyperbaric treatment in children with autism have reported clinical improvements; however, this treatment has not been evaluated to date with a controlled study. We performed a multicenter, randomized, double-blind, controlled trial to assess the efficacy of hyperbaric treatment in children with autism.

METHODS: 62 children with autism recruited from 6 centers, ages 2-7 years (mean 4.92 +/- 1.21), were randomly assigned to 40 hourly treatments of either hyperbaric treatment at 1.3 atmosphere (atm) and 24% oxygen ("treatment group", n = 33) or slightly pressurized room air at 1.03 atm and 21% oxygen ("control group", n = 29). Outcome measures included Clinical Global Impression (CGI) scale, Aberrant Behavior Checklist (ABC), and Autism Treatment Evaluation Checklist (ATEC).

RESULTS: After 40 sessions, mean physician CGI scores significantly improved in the treatment group compared to controls in overall functioning (p = 0.0008), receptive language (p < 0.0001), social interaction (p = 0.0473), and eye contact (p = 0.0102); 9/30 children (30%) in the treatment group were rated as "very much improved" or "much improved" compared to 2/26 (8%) of controls (p = 0.0471); 24/30 (80%) in the treatment group improved compared to 10/26 (38%) of controls (p = 0.0024). Mean parental CGI scores significantly improved in the treatment group compared to controls in overall functioning (p = 0.0336), receptive language (p = 0.0168), and eye contact (p = 0.0322). On the ABC, significant improvements were observed in the treatment group in total score, irritability, stereotypy, hyperactivity, and speech (p < 0.03 for each), but not in the control group. In the treatment group compared to the control group, mean changes on the ABC total score and subscales were similar except a greater number of children improved in irritability (p = 0.0311). On the ATEC, sensory/cognitive awareness significantly improved (p = 0.0367) in the treatment group compared to the control group. Post-hoc analysis indicated that children over age 5 and children with lower initial autism severity had the most robust improvements. Hyperbaric treatment was safe and well-tolerated.

CONCLUSION: Children with autism who received hyperbaric treatment at 1.3 atm and 24% oxygen for 40 hourly sessions had significant improvements in overall functioning, receptive language, social interaction, eye contact, and sensory/cognitive awareness compared to children who received slightly pressurized room air.

Issues to consider with this research:

- Empirical – YES
- Reviewed by peers – YES
- Evidence measurable and objective – NO
- Reproduced - ?

*Participants in centers – learning going on? Other variables
Measured improvements with CGI rating scale (Clinical
Global Impressions) – subjective? – why not a definite
count of, for example, receptive skills*

Association for Science in Autism Treatment's review of the study:

- Strength of the study: the control group
- Limitations:
 - many of the outcome measures are not valid measures of change
 - there was no test of whether children actually absorbed the oxygen administered
 - parents may have been aware that their child was or was not receiving HBOT, while they were present in the chamber, even though they were not told directly
 - the authors did not measure outcomes after treatment ended to determine whether effects lasted

For further information on choosing interventions based on solid scientific evidence consider attending:

Hank Schlinger's presentation (session # 62)
on Thurs 4th August from 9-12:

“Evaluating Autism Treatments: Science
and Pseudoscience”

Sources of information:

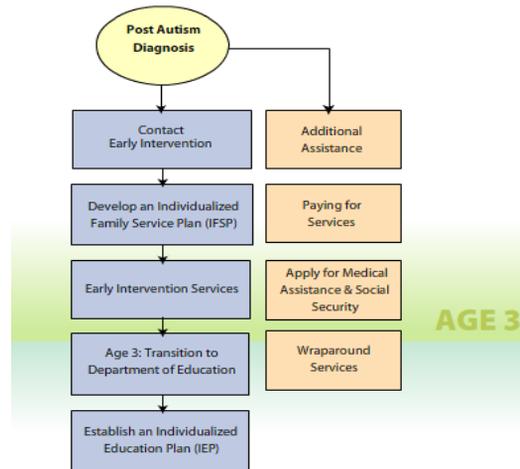
- Bureau of Autism Services
www.dpw.state.pa.us
- ASERT
www.paautism.org
- PaTTAN
www.pattan.net

Diagnosis, Research, then what?

- INTERVENTION!

Diagnosis, Research, then what?

If individual is birth – 3 years old:



Individuals with Disabilities Education Act

- IDEA
- Nation's special education law
- Defines processes of evaluating eligibility
 - creating an IEP
 - providing services
 - measuring progress
 - reevaluating

Evaluating Eligibility

- Individual identified as possibly needing special education services and related services
 - By school professional
 - By parent

Parent consent needed before individual evaluated!

Evaluation

- All areas related to the disability
- Conducted by professionals
- Results – decide eligibility
 - decide appropriate placement
- Parental input

Eligibility determined

- Group of qualified professionals AND parents (IEP team) look at evaluation and decide if individual meets the requirements of being:

“A child with a disability” (IDEA)

and

“who, by reason thereof, needs special education and related services.” (IDEA)

Eligibility determined

According to IDEA, there is NO requirement to get a medical diagnosis of any autism spectrum disorder for your child to be considered “educationally autistic”

- . For school purposes, your child has to meet only the following definition:

Educational Definition of Autism (IDEA)

Autism means a developmental disability significantly affecting verbal and nonverbal communication evident before age 3, that adversely affects a child's educational performance.

Faces of Autism: Ethan

- Once individual found eligible for services there must be a meeting within 30 calendar days to write the IEP

Creating the IEP

The IEP is:

- a team approach
- an assessment of the individual

An IEP identifies:

- Strengths, challenges and needs
- Potential goals
- New Information from parent(s)

Heward's metaphor for the IEP:

“ The IEP is a system for spelling out...where the child [is]with current skills, where she should be going, how she will get there, how long it will take, and how to tell if and when she has arrived. Thus, a good IEP serves as both a road map and a guidebook for meeting the challenges posed by a student's disability. The annual goals and benchmarks developed by the team identify the destinations for the journey and provide signposts along the way.”
(Heward, 2006)

SMART IEPs:

S – Specific
M- Measurable
A- Action words
R – Realistic/Relevant
T – Time specific

Patricia Howey, 2006

IEPs should include:

- Current performance
- Annual goals
- Special Education and related services required
- Participation with nondisabled peers
 - Must explain the extent(if any) to which a child will not participate with non-disabled peers in regular classes or other activities

IEPs should include (continued):

- Participation in state and district-wide tests
- Dates and places
- Transition services planning (beg. 14 yrs)
- Transition services needs (beg. 16 yrs)
- How progress will be measured

FAPE and LRE

- In Pennsylvania, IEP teams are required to adhere to the following guidelines when making educational placement decisions:
 - A free and appropriate public education (FAPE) must be provided to every student with an IEP
 - FAPE must be delivered in the least restrictive environment (LRE) as decided by the IEP team.

Remember:

- The general education environment is always the first option for individuals with ASD
- Individuals with ASD have the right to access typically developing peers

Least Restrictive Environment (LRE)

- IDEA supports inclusive practices by requiring that:
 - “to the maximum extent appropriate, children with disabilities.....are educated with children that are nondisabled”
 - “special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity is such that education in regular classes with the use of supplementary aids and services, cannot be achieved satisfactorily”

(IDEA, 1997).

Least Restrictive Environment (LRE)

- IDEA requires:
 - availability of a continuum of placements varying in their restrictiveness to ensure that all needs are met.
 - Pennsylvania school districts maintain the required continuum of placements that are designed to provide a rich supply of diverse programs that support sound inclusive practices.

Placement

Based on:

- IEP
- Strengths, challenges and needs

IEP needs to be:

- Framed around how to help the child:
 - Advance towards annual goals
 - Be involved in the general curriculum
 - Participate in extracurricular activities and nonacademic activities

Providing Services

- Parents should be given copy of the IEP
- All teachers and service providers should have access to the IEP to know their specific responsibilities

Measuring progress

- Progress should be measured – DATA!
- Reported to parents
 - Minimally progress reported at the same frequency as a nondisabled child's progress is reported

Reviewing the IEP

- At least 1 time a year
- Parent or school can ask for a review at any point
- Parents attend IEP meetings, make suggestions, agree or disagree with goals or placement

Re-Evaluation

- At least every 3 years
- Or before if:
 - Conditions warrant
 - Parent/Teacher asks
- Assesses whether the individual is still “a child with a disability” (IDEA) and reviews level of their current needs

Remember:

- Throughout this process it is important that everyone understands both the child and the world in which he or she lives.
- Changing the environment is the only tool we have to make life better for our children

In summary.....

Diagnosis can assist in:

- Specifying interventions
- Understanding Autism
- Accessing helpful information

But:

- Diagnosis is not enough, we will need more information to be able to program for our children and make a difference in their lives

Autism 101 presentations

- During this week the following Autism 101 presentations will cover intervention in more detail:

EFFECTIVE ASSESSMENT
INSTRUCTION BASICS
BEHAVIOR MANAGEMENT

Effective Assessment:

- Presenter : Katie Staub
- Date and time: 8/2/11 1-4pm
 - Review of the importance of assessment
 - Strategies for completing an assessment
 - Strategies for reviewing educational environments and programs
 - Consideration of how to assess a wide range of skills

Instruction Basics

- Presenter: Amiris Dipuglia
- Date/Time: 08/3/11 9-12
- Strategies and procedures to deliver high quality instruction
- Focus on evidence based interventions that address the core issues of ASD
- Emphasis on training, data based decisions and team communication

Behavior Management

Presenter: Linda Franchock

Date/Time: 08/03/11 1-4pm

- Positive approaches to managing common problem behaviors
- Methods for reducing occurrence of challenging behaviors
- Review of wide range of factors that can influence behaviors
- Emphasis will be on a functional approach that considers individual's skills and abilities as well as variables in the environment

Some important things to remember:

- The individuals we love and work with are not “autistic individuals” they are “individuals with autism”
 - People with ASD are individuals first
 - People with ASD respond to the world around them
 - There are no new principles of learning that apply only to individuals with ASD: the evidence shows that, like all students, students with autism respond to good instruction!

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- PaTTAN. (2009). *Using Applied Behavior Analysis to Educate Students with Autism in Inclusive Environments* [Brochure]

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Thank You
For
Attending

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Commonwealth of Pennsylvania
Tom Corbett, Governor

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