AUTISM CENTRAL PA
CENTRAL PA REGIONAL AUTISM PARTNERSHIP
PENN STATE COLLEGE OF MEDICINE
PHILHAVEN
THE VISTA FOUNDATION

UNDERSTANDING MORE PIECES TO THE PUZZLE

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Goals for tonight

- Provide essential information and resources to should consider after a child has been diagnosed with an ASD
  - What are ASDs?
  - What are interventions for ASDs?
  - What supports do families need?
- Discuss public education policy
  - Children in the classroom
- Highlight treatment and interventions available for ASDs

Essential Information about ASDs

What is an ASD (Autism Spectrum Disorder)?

- Complex developmental disabilities that include a range of disorders…
  - Autistic Disorder
  - Asperger's Disorder
  - Pervasive Developmental Disorder, NOS
- …and are characterized by a certain set of behaviors…
  - Social impairments
  - Verbal and nonverbal communication difficulties
  - Restricted and repetitive behavior or interests
- …and are "spectrum disorders" — affecting individuals differently and to varying degrees.

Accompanying conditions

- Seizure disorders/epilepsy (~25%)
- Genetic disorders (2 – 5%)
- Intellectual disabilities
  - ~ 25 – 70% (more in those diagnosed with Autistic Disorder)
  - ~ 10% for diagnoses of Asperger's or PDD NOS
- Sensory sensitivities
- Anxiety disorders
- GI disorders
  - Ranges from chronic constipation to diarrhea
- Sleep issues
  - Problems falling and staying asleep

Unique abilities that may accompany an ASD

- Rote memory skills
- Computer skills
- Musical and artistic ability
- Honesty
- Ability to be extremely focused
- A small proportion will have unusual talents or skills (savants)

It is important to build on these strengths and interests!

How common are ASDs?

- 1990: 4 in 10,000 children were diagnosed with Autistic Disorder
- 2000: 1 in 166 children
- ***2009: 1 in 110 children (67 children are diagnosed per day)***
  - Why this increase?
  - Where were the people with ASD before?
- Males are 4 times more likely to be diagnosed with an ASD than females
  - 1 in 94 boys

Causes of ASDs

- ***Scientists aren't certain about what causes ASDs, but most agree there is no single cause – it's likely that both genetics and environment play a role***
- Biology
  - Abnormal brain development and structure
- Genetics
  - Some genes make more people likely to have an ASD or may leave them more vulnerable to environmental triggers

What are *not* causes of ASDs

- Vaccines
  - No scientific link has been found between the administration of vaccines and ASDs
  - Research examining environmental factors (e.g., mercury, lead, other heavy metals) is ongoing

ASDs are ***not*** caused by bad parenting!

How are ASDs diagnosed?

- Screening
  - American Academy of Pediatrics guidelines for pediatricians and family physicians: screening should be completed at 18- and 30-*month well-child check
    - M-CHAT
      - *Available on the ASERT website*
    - Checklist for Autism Spectrum Disorders
- Can often be reliably detected by age 3, although sometimes as early as 12- to 18-months
  - Who can diagnose?
  - What does the process entail?

How are ASDs diagnosed?

- Why does a child benefit from a diagnosis?
  - A diagnosis does not change the child but it…
    - Suggests a road map for treatment – may point to certain interventions that might be more effective
    - Helps access ASD specific services through early intervention or education programs
    - Helps to understand behavior and development
    - Helps us pay attention to skills or problems we might have overlooked
    - Links parents together in a supportive community

Children diagnosed with ASDs in the Classroom

A review of acronyms…

- IDEA (Individuals with Disabilities Education Act)
- MDE (Multidisciplinary Evaluation)
- IEP (Individualized Education Plan)
- NOREP (Notice of Recommended Educational Placement)
- FAPE (Free Appropriate Public Education)
- LRE (Least Restrictive Environment)

What are your child's rights to public education?

- IDEA – federally mandated program ***assuring free and appropriate public education*** for children with diagnosed learning deficits (www.idea.ed.gov)
  - An education that is reasonably calculated to afford a child ***meaningful progress***

What is the process?
Step 1: The MDE

- A comprehensive evaluation by a multidisciplinary team which may include a psychologist, psychiatrist, neurologist, speech therapist, etc.
  - Genetic testing
  - Cognitive testing
  - Language testing
  - Hearing assessment
  - Structured diagnostic assessments (ADOS, ADI-R)
  - Completing of questionnaires
- Determines eligibility for services and level of need

Step 2: the IEP

- An agreement between the school and family on the child's goals
  - Once the plan is written, but sure your concerns are addressed and the child's strengths are noted
- Meets annually to review progress and change goals as needed
  - *Parents can request additional meetings at any time*
- *Who attends?*
  - ***Caregiver(s)***
  - ***One special education teacher***
  - ***Representative of the school***
  - *Someone who can interpret results of the evaluation**
  - *At least one regular education teacher**
  - *Any other personnel at the request of school/parent**
  - *The child (if appropriate)**

Least Restrictive Environment (LRE)

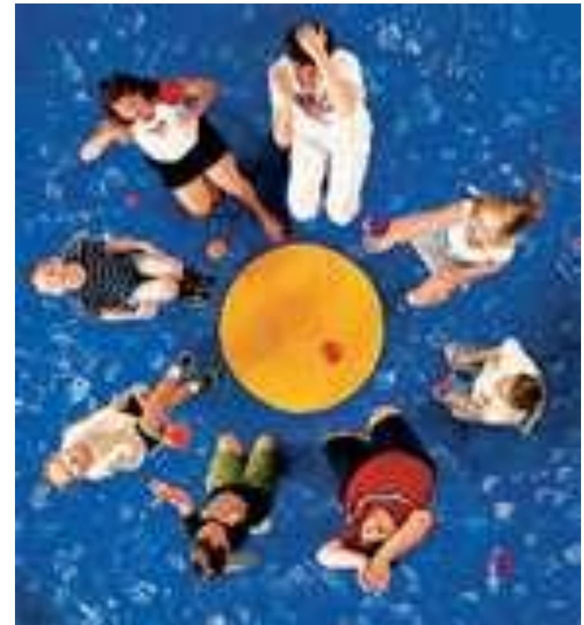
- A disabled child should be placed in the LRE that will provide him/her with ***a meaningful educational benefit*** – it needs to be appropriate to the child's individual needs
  - May not always be a special education classroom
  - "The LRE is the one that, ***to the greatest extent possible,*** satisfactorily educates disabled children together with children who are not disabled, in the same school the disabled child would attend if the child were not disabled"

The teacher's role

- Helps to coordinate and integrate services
- Looks at whole child and integrates learning
  - Fine/Gross motor
  - Social/emotional
  - Cognitive
  - Self-help skills
  - Language
  - Sensory
- Play is the medium for learning

Educators, therapists, & caregivers

- All overlap and supplement each other
  - ***COMMUNICATION IS IMPORTANT***
- The caregiver is the expert on the *child*
- The therapist is the expert on the *particular skill area*
- The teacher is the expert at *integrating individual goals into the classroom or home*



The classroom environment

- Provides opportunities to practice and try out new skills in the company of other children
- Child centered, directed and focused
- Focus on process, not content
- Build on successes and strengths
- School age children usually have school-based, individualized, special education
  - May be in a separate class with other children diagnosed with an ASD, or in an inclusion classroom for part of the day
  - Each program may use different locales or methods, but all should provide **structure that will help children learn social skills and functional communication**

Classroom accommodations

- Accommodations are made to the regular class to account for the individual child's learning differences
  - A child who fidgets may be encouraged to use a squeeze toy or sit on a balance ball to help him focus
  - An anxious child can be provided with access to a calendar to refer to a picture schedule of activities
  - A child overwhelmed by "visual clutter" on a page may need duplicate worksheets with large font and few problems per page
- Teachers use a multitude of methods to support children throughout the day (e.g., social stories, picture schedules, visual cues, tactile cues, auditory cues)
- *All of this is within regular class activities*

Goals through the school years

- Elementary school
  - Target delayed areas while encouraging growth in areas of strength
  - Learning how to act in social situations, making friends
  - If able to handle academic work, should help with organizational skills and minimizing distractions
- Middle and high school
  - Target practical matters such as work, community living, and recreational activities

Treatments/ Interventions

What should all ASD education and treatment programs include?

- ***There is no single best treatment for all children with an ASD, but everyone agrees that intervention is essential***

- ***Ideal treatment coordinates therapist and interventions that meet the specific needs of individual children***
  - Highly structured, specialized programs are key

- ***Collaborating with educators is essential***

What should all ASD education and treatment programs include?

- ***There is no cure for ASD***
  - Treatments are designed to remedy symptoms

- ***Treatment plans should define objectives and set measurable goals***
  - These should be re-examined every 3 – 4 months and *at least* annually

Questions to ask regarding ASD education and treatment programs

- How does treatment occur?
  - Who implements it?
  - Where does it occur?
  - What does a session look like?
  - How often does it occur?
- How is this treatment different from others?
- Is there evidence that this treatment is effective?
- How are caregivers involved?

What professionals most frequently intervene?

- School personnel
  - Teachers
  - Counselors
- Therapists (social-emotional)
  - Psychologists (Clinical, School) – Doctorate
  - Board Certified Behavior Analyst (BCBAs) – Masters + certification
    - BCBA – D – Doctorate + certification
  - Behavioral Specialists (BSC) – Masters
  - Mobile Therapists – Masters
  - Social Workers – Masters
  - Therapeutic Support Staff (TSS) – Bachelors

What professionals most frequently intervene?

- Speech-Language Pathologists (SLPs) – Masters* + certification
- Occupational Therapists (OTs) – Masters* + certification
- Physical Therapists (PTs) – Masters* + certificiation
- Physicians – Doctorate
  - Psychiatrist
  - Neurologist
  - Pediatrician/Developmental Pediatrician
  - Family Physician
- Nurses

*Masters degree or higher

Treatment 1: Applied Behavior Analysis (ABA)

- Surgeon General: *"Thirty years of research has demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and increasing communication, learning, and appropriate social behavior"*
- Consists of…
  - Building on child's interests
  - Predictable schedules
  - Teaches tasks in a series of simple steps
  - Engages the child in highly structured activities
  - Provides regular reinforcement of behavior
  - Includes parental involvement

Treatment 1: Applied Behavior Analysis (ABA)

- Different “brands” of ABA
  - Early Intensive Behavioral Intervention (EIBI)
  - Discrete Trial Training/Lovaas Model
  - Verbal Behavior (VB)
  - Pivotal Response Training (PRT)
  - Competent Learner Model (CLM)
  - STAR Program

What ABA is…	What ABA is not…
Use of reinforcment	NOT just token economies (M&M's and Tootsie Rolls)
Break down of complex tasks into individual steps to teach	NOT teaching drills that produce "robot-like" behavior
Individualized for the student	NOT a "one-size fits all" approach
Combination of Intensive Teaching and Natural Environment Teaching	NOT synonymous with Discrete Trial Training
Data-based	NOT harmful or uncomfortable for children

Treatment 1:
Applied Behavior Analysis (ABA)

- Who: BCBA*
- Where: Home, community, school or outpatient setting
- What: Mix of table-top and floor-based activities, based on the child's needs
- How often: Variable (1 session – "full time"), dependent on child's needs
- More information…
  - Behavior Analyst Certification Board (www.bacb.com) – "Certificant Registry"
  - Autism Speaks (www.autismspeaks.org/whattodo/what_is_aba.php)

Treatment 2: Cognitive-Behavioral Therapy (CBT)

- Psychotherapy approach that aims to solve problems concerning dysfunctional emotions, behaviors and cognitions
- Best to treat comorbid anxiety and depression in individuals with high-functioning ASDs
- Who: Psychologist specializing in CBT
- Where: Hospital/outpatient or school setting
- What: "Talk" therapy + homework
- How often: Typically 1 hour per week
- More information…
  - Association for Behavioral and Cognitive Therapies (www.abct.org) – "Find a Therapist"

Treatment 3:
Speech & Language Therapy

- Book reading activities
  - Receptive/expressive vocabulary
  - Wh- questions
  - Story sequencing
- Language expansion activities
- Play based activities
  - Functional play
  - Imaginative play
- Social skills building activities
  - Structured play dates
  - Turn taking activities

Treatment 3: Speech & Language Therapy

- Who: A licensed SLP
- Where: School or outpatient setting
- What: Mix of table-top and floor-based activities, based on the child's needs
- How often: Typically 1 – 3 times per week, based on child's needs
- More information…
  - American Speech-Language Hearing Association (www.ASHA.org) – parent's page

Treatment 4: Occupational Therapy

- OT's role is to assure the child's mastery of his/her main occupations (play, exploration of the environment, new learning, self-care, being a family member, being a student, etc.)
- Who: A licensed OT or certified assistant
- Where: Community, school or outpatient setting
- What: Mix of table-top and floor-based activities, based on the child's needs (touch, movement, etc.)
- How often: Typically 1 – 3 times per week, based on child's needs
- More information…
  - American Occupational Therapy Association (www.aota.org)

Treatment 5: Physical Therapy

- PT's role is to treat individuals with conditional that limit their ability to move and perform functional activities in daily life
- Who: A licensed PT
- Where: Hospital, school or outpatient setting
- What: Floor-based activities, based on the child's needs (going up/down stairs, balance, toe walking etc.)
- How often: Typically 1 – 3 times per week, based on child's needs
- More information…
  - American Physical Therapy Association (www.apta.org)

Occupational Therapy vs. Physical Therapy

- Occupational Therapy
  - Daily occupations (ADLs)
  - Activities at home, play, and school
  - Includes fine motor (e.g., writing)

- Physical Therapy
  - Gross motor
  - Focuses on lower extremities
    - Running
    - Jumping
    - Balancing

How do I choose an intervention?

- Match your child's learning style
  - Probably use a combination of treatments
- Make sure it is convenient for your family
  - Consider *all* costs
    - Impact on family harmony
    - Time to implement program
    - Access to services
    - Literal cost (covered by insurance?)

Evidence Based Practice Guidelines

- Standard of practice
- The use of research and scientific studies as a base for determining the best practices in a field
- Make sure…
  - You talk to people you have a relationship with and trust about a potential intervention
  - The intervention is scientifically sound and well-documented
  - You understand the intervention's limitations, with whom it words, and for what skill
  - You are informed about the type, degree, and rapidity of the change you should expect

Results of National Standards Report

Established	**Emerging**		***Unestablished***
Antecedent Pkg.	AAC Devices	Music Therapy	*Academic*
Behavioral Pkg.	Cog Behavioral	Peer-mediated	*Auditory Integration*
Comp. Behavior	Develop-Relation	PECS	*Facilitated Comm.*
Joint Attention	Exercise	Reductive Pkg.	*Gluten-Casein Free*
Modeling	Exposure Pkg.	Scripting	*Sensory Integration*
Natural. Teaching	Imitation Based	Sign Instruction	
Peer Training Pkg.	Initiation Training	Social-Comm. Inst.	
Pivotal Response	Language Training	Social Skills	
Schedules	Massage/Touch	Structured Teach	
Story Based	Multi-component	Technology	
		Theory of Mind	

Evidence Based Practice Guidelines

- Interventions that have been reported to have been helpful to some children, but whose efficacy or safety has not been supported
  - Dietary interventions (gluten-free, casein-free; Vitamin B6 + magnesium, secretin)
    - Nutritional status should be measured carefully
  - Medications
    - Often use to treatment behavioral and/or emotional problems associated with ASDs
    - Several meds are FDA approved, but it is important to work with a doctor, preferably a psychiatrist, who has experience with children with ASDs

Current ASD Research

ASERT Centers

- Western Region (Pittsburgh)
  - Center for Autism and Developmental Disorders at the Western Psychiatric Institute and Clinic
  - Watson Institute
  - Dr. Gertrude Barber National Institute
  - Children's Hospital of Pittsburgh of UPMC
  - University of Pittsburgh
- **Central Region (Hershey and Lancaster)**
  - **Penn State Hershey Medical Center**
  - **The Vista School**
  - **Philhaven's Center for Autism and Developmental Disabilities (CADD)**
- Eastern Region (Philadelphia)
  - Center for Autism Research (CAR) at the Children's Hospital of Philadelphia
  - University of Pennsylvania
  - Drexel University
  - Lehigh University

Who we are…Autism Central PA

- **A**utism
- **S**ervice
  - Screening
  - Improving age of diagnosis
- **E**ducation & Outreach
  - Community education (e.g., schools, family physicians)
- **R**esearch
  - Social Skills Training
  - Toilet Training
  - Diagnostic tools
- **T**raining

ASERT Resource Center

- Website (www.AutismCentralPA.org/)
  - Check the blog!
- Email
- Call
- Facebook
- Twitter

Additional Resources

- Autism Speaks (www.autismspeaks.org)
- PA BAS (Bureau of Autism Services) (www.dpw.state.ps.us/ServicesPrograms/Autism)
- Organization of Autism Research (www.researchautism.org)
- PaTTAN (www.pattan.k12.pa.us)
- National Standards Project (www.nationalautismcenter.org/about/national.php)

THANK YOU!

QUESTIONS?

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