



Commission for Children with  
Special Health Care Needs

# Commission for Children with Special Health Care Needs

## Office of Autism: **The Fundamentals of Autism Spectrum Disorder**



# Goals of the Presentation:

- Brief History of Autism
- Definition of ASD
- Signs, Symptoms, Red Flags
- Treatment
- Resources



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# Historical Perspective



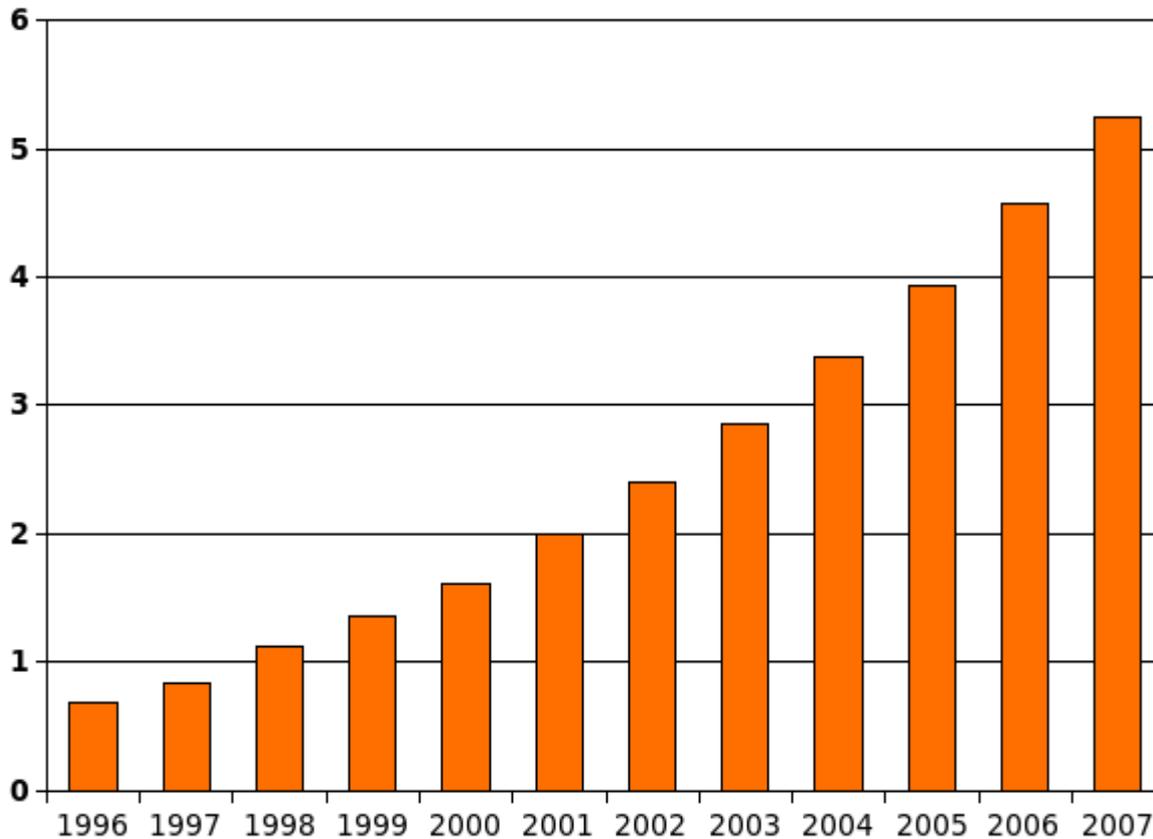
- ❖ **1943** Leo Kanner, “early infantile autism”
- ❖ **1944** Hans Asperger, “autistic pathology”
- ❖ **1952 DSM-I** The first edition of the Diagnostic and Statistical Manual of Mental Disorders is released. The manual provides a standard criteria for the diagnosis of mental disorders. In this first edition, autistic-like symptoms are classified under childhood schizophrenia. Autism is not given a separate diagnosis.
- ❖ **1950-60** Early theorists believed that ASDs were caused by non-responsive, cold, and rejecting parents “refrigerator moms”



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- ❖ **1968 DSM-II** Like the previous edition, the second edition of the DSM classifies autism under the umbrella diagnosis of schizophrenia.
- ❖ **1980 DSM-III** In the third edition of the DSM, autism receives a separate diagnostic category for the first time
- ❖ **1994 DSM-IV** adds several subtypes to the "autism spectrum," including Asperger's (50 years after it is identified), Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- ❖ **2013 DSM-5** With the release of the fifth edition of the DSM, subtypes of autism spectrum disorder (Asperger's and Rett's) are eliminated.





Bar chart of the number (per 1,000 U.S. resident children aged 6–17) of children aged 6–17 who were served under the Individuals with Disabilities Education Act (IDEA) with a diagnosis of autism, from 1996 through 2007.



The number of autism diagnoses increases in the 2000s, and autism is described as an “epidemic” by the CDC.

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# Historical Medical Diagnostic Categories:



- Autism, Aspergers, Autism Spectrum Disorder, ASD, Pervasive Developmental Disorder, PDD, PDD NOS, Autistic Disorder
- Clinicians often use the terms Pervasive Developmental Disorder, PDD, which comes from the DSM IV-Revised
- Parents and Persons affected by Autism Spectrum Disorder (which includes Autistic Disorder, Aspergers, and PDD NOS)



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# Prevalence of ASD

- Knows no racial, ethnic, or social boundaries
- Five times more prevalent in boys (1 in 42) than girls (1 in 189)
- Usually affects sensory and motor processing systems of the brain
- Varying degrees of severity in different thus the term spectrum

Centers for Disease Control, 2014



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# Prevalence Rate of ASD



- ❖ ADDM Network -The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to estimate the number of children with autism spectrum disorder (ASD) and other developmental disabilities living in different areas of the United States.
- ❖ Data from an earlier report of the CDC's Atlanta-based program found the rate of autism spectrum disorder was 3.4 per 1,000 for children 3 to 10 years of age.

**CDC estimates that 1 in 68 children (ages 0-8) in the  
ADDM study had been diagnosed with an ASD**

Per CDC 2015



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# ASD Prevalence Rate Compared



- ASD compared to the prevalence of other childhood conditions, this rate is lower than the rate of intellectual disability (9.7 per 1,000 children)
- ADHD approximately 11% of children 4-17 years of age (6.4 million) have been diagnosed with ADHD as of 2011.
  - The percentage of children with an ADHD diagnosis continues to increase, from 7.8% in 2003 to 9.5% in 2007 and to 11.0% in 2011.
  - Rates of ADHD diagnosis increased an average of 3% per year from 1997 to 2006 and an average of approximately 5% per year from 2003 to 2011. (CDC)
- **Higher** than the rates for **cerebral palsy** (2.8 per 1,000 children), **hearing loss** (1.1 per 1,000 children), and **vision impairment** (0.9 per 1,000 children). Per CDC 2015



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# Possible explanations for increase



- ❑ Changes in diagnostic criteria
  - ❑ Diagnostic substitutions
- ❑ Increasing availability of services
- ❑ Increased Awareness through Social Marketing, Media, Hollywood.



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# What ASD is not:

- A mental illness
- The result of bad parenting
- Unruly individuals who choose not to behave
- Always associated with mental impairment
- Always associated with behavioral challenges
- Outgrown or a stage
- The same in every child



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# Myths About ASD

What do you think when someone says  
Autism?

Savant

No empathy

Aggressive

Can't Communicate

Can't make friends

Parent's fault

Bad Behavior



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# Myths



- Persons with Autism aren't social
- Persons with Autism do not form attachments
- Persons with Autism don't like to be touched. (Some persons may have sensory extremes of feeling no pain or hypersensitivity to touch where light touch feels painful)



# What is Autism Spectrum Disorder?



Autism spectrum disorder is a neurodevelopmental disorder that impairs one's ability to communicate and interact with others. It also includes restricted repetitive behaviors, interests and activities. These issues cause significant impairment in social, occupational and other areas of functioning.

Mayo Clinic 2015



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# ADA Definition of Disability



- Individual has a physical or mental disability that substantially limits one or more life activities (self-care, manual tasks, walking, seeing, hearing, speaking, learning, working)
- Individual has a record of a physical or mental disability
- Individual is regarded as having a disability



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# Intellectual Disability



Correct term instead of “mental retardation”

- **Intellectual disability** is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18.
- **Intellectual functioning**—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving.

<http://aaidd.org/intellectual-disability>



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# Developmental Disability

- Manifests before age 22
- Likely to continue indefinitely
- Results in substantial functional limitations in 3 or more areas of life activity:
  - Self-care
  - Receptive or expressive language
  - Learning
  - Mobility
  - Self-direction
  - Capacity for independent living
  - Economic self-sufficiency



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# Developmental Disabilities

## Examples



- **Cognitive Disabilities**
  - **Cerebral Palsy**
  - **Muscular Dystrophy**
    - **Autism**
  - **Down Syndrome**



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# Five major changes to ASD diagnosis in the DSM 5



1. New classification system eliminates the previously separate subcategories on the autism spectrum, including Asperger syndrome, PDD-NOS, childhood disintegrative disorder and autistic disorder. **These subcategories will be folded into the broad term autism spectrum disorder (ASD).**



## Diagnostic Changes #2

### DSM IV

#### Three domains:

- Social Impairment
- Language  
Communication  
Impairment
- Repetitive/restricted/  
stereotyped behaviors
- At least 6 out of 12  
deficits in the three  
domain areas



### DSM 5



#### Two Categories:

- *Social Communication  
Impairment*
- 3 deficits in social communication
- *Restricted interests/repetitive  
behavior*
  - 2 deficits repetitive  
behavior/restricted interest

#### **New symptom:**

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

# DSM 5

## Change # 2.



### Categories

#### Two Categories:

Social Communication Impairment  
Restricted interests/repetitive behaviors

#### Diagnosis Requirements

3 deficits in social communication  
At least 2 symptoms in Restricted Repetitive Patterns  
of Behavior/Interests

**New symptom:** Hyper- or hypo-reactivity to sensory input or  
unusual interests in sensory aspects of the environment



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# Diagnostic Changes cont.



# 3 Symptoms can currently be present, or reported in past history.

# 4 In addition to the diagnosis, each person evaluated will also be described in terms of:

- Any known genetic cause (e.g., fragile X syndrome, Rett syndrome)
- Level of language
- Intellectual disability
- Presence of medical conditions such as seizures, anxiety, depression, and/or gastrointestinal (GI) problems



# Diagnostic Changes #5



The work group added a new category called Social Communication Disorder (SCD). This will allow for a diagnosis of disabilities in social communication without the presence of repetitive behaviors.



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# Deficits in Communication



A. Persistent deficits in social communication and social interaction across multiple contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

- Deficits in social-emotional reciprocity
- Deficits in nonverbal communicative behaviors used for social interaction
- Deficits in developing, maintaining, and understanding relationships



# Determining Restricted, Repetitive Behavior



- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least 2 of the following:
- Stereotyped or repetitive motor movements, use of objects, or speech
  - Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
  - Highly restricted, fixated interests that are abnormal in intensity or focus
  - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment





| <b>Dimensional Ratings<br/>for DSM V ASD</b> | <b>Social Communication</b>  | <b>Fixated Interests and<br/>Repetitive Behaviors</b>   |
|--|--|---|
| <b>Requires very<br/>substantial support</b> | <b>Severe deficits in verbal and nonverbal. Very limited initiation of social interactions and minimal response to overtures.</b>                      | <b>Inflexibility of behavior, extreme difficulty coping with change, RRBs that markedly interfere in all spheres. Great Distress</b>          |
| <b>Requires substantial<br/>support</b>      | <b>Marked deficits with limited initiations and reduced or atypical responses. Impairment apparent even with supports in place.</b>                    | <b>Inflexible in behavior, difficulty coping with change, frequent RRBs and interfere in a variety of contexts. Some distress.</b>            |
| <b>Requires support</b>                      | <b>With or without supports, noticeable impairments. Difficulty initiating social interactions and clear atypical responses. Maybe decrease social</b> | <b>Behavioral inflexibility causes significant interference in one or more contexts. Trouble switching. Problems organizing and planning.</b> |

# Possible Causes



Areas researched for cause:

- Environmental toxins
- Genetic vulnerability
- Research is beginning to show a genetic link with an environmental trigger



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# Brain Development in ASD



- Differences in brain development
- Increased head size (20-30% of young children);
- Differences in specific areas of brain (frontal cortex, basal ganglia, cerebellar regions)
- Differences in patterns of connections among brain cells



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## Major Brain Structures Implicated in Autism

**Cerebral cortex** - a thin layer of gray matter on the surface of the cerebral hemispheres. Two-thirds of its area is deep in the fissures or folds. Responsible for the higher mental functions, general movement, perception, and behavioral reactions.

**Amygdala** - responsible for emotional responses, including aggressive behavior.

**Hippocampus** - makes it possible to remember new information and recent events.

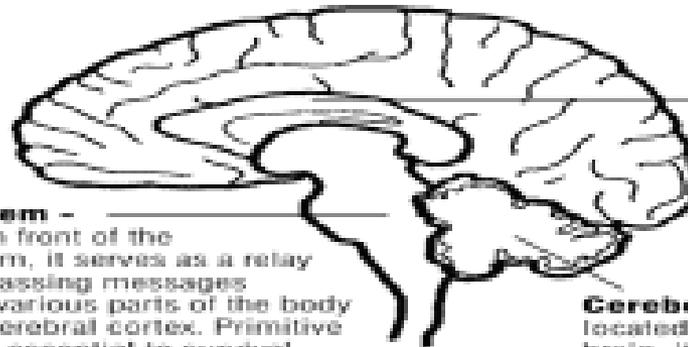
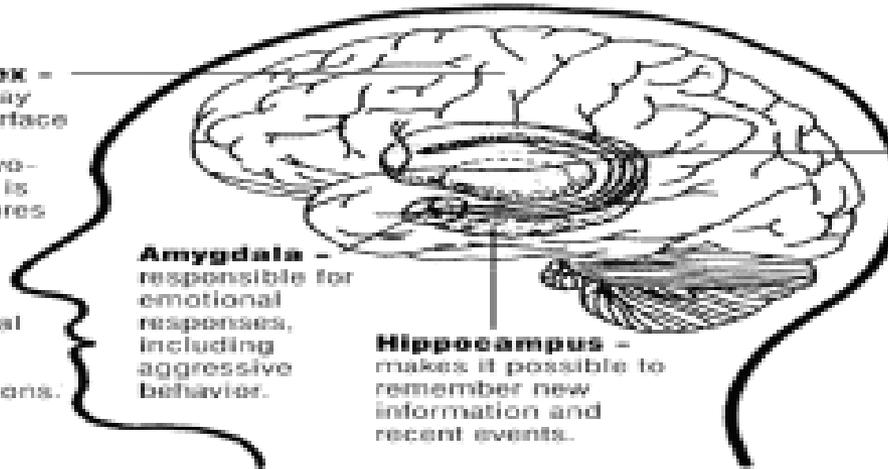
**Basal ganglia** - gray masses deep in the cerebral hemisphere that serves as a connection between the cerebrum and cerebellum. Helps to regulate automatic movement.

### Major Brain Structures Implicated in Autism

**Brain stem** - located in front of the cerebellum, it serves as a relay station, passing messages between various parts of the body and the cerebral cortex. Primitive functions essential to survival (breathing and heart rate control) are located here.

**Corpus callosum** - consists primarily of closely packed bundles of fibers that connect the right and left hemisphere and allows for communication between the hemispheres.

**Cerebellum** - located at the back of the brain, it fine tunes our motor activity, regulates balance, body movements, coordination, and the muscles used in speaking.



# Impairment in Communication:



- Lack of showing gestures
- Lack of coordination of nonverbal communication
- Unusual prosody (little variation in pitch, odd intonation, irregular rhythm, unusual voice quality)
- Delayed speech and language skills



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# Theory of Mind



- The ability to make inferences about what other people believe to be true
  - Perspective taking
  - Difficulty anticipating what others will say or do in various situations
  - Understanding intention in communication



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# Communication

- Delayed and atypical communication and language development
  - 30-50% of individuals with autism have no useful spoken language need citation
  - Majority of those with fluent language have atypical language development
  - Regression in early communication skills seen in 25%-30% of individuals in the spectrum
  - Language regression after normal language onset is *unique* to autism



# Communication challenges:



- Common language characteristics
  - Unusual tone of voice and inflection
  - Reversing pronouns
  - Lacking variety in sentence structure
  - Using simplistic and immature grammar
- Other characteristics
  - Overly formal speech (little professor)
  - Echolalia (repeating what they heard over and over)
  - Inability to generalize learned communication skills
  - Lack of reciprocity



# Impairment in Social Interaction:



- Does not participate in or enjoy pretend play
- Poor joint attention
- Poor response to social bids
- Lack of appropriate eye gaze
- Lack of warm, joyful expressions
- Lack of sharing interest or enjoyment
- Lack of response to name



# Repetitive Behaviors and Restricted Interests:



- Repetitive movements with objects
- Repetitive movements or posturing of body, arms, hands or fingers
- Rapid hand movement by eyes
- Likes parts of objects
- Has to follow certain routines
- Flaps hands, rocks body, or spins self in circles



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# Sensory Challenges



- What does over stimulation mean?
  - The five senses are on overload

Example: Walmart, shopping malls, lunch rooms
- Persons with Autism often have a more sensitive nervous system therefore they may be more observant and preoccupied with the details





# Sensory Challenges

- Heightened or decreased experience of sounds, lights, movement, touch, smell or taste or fascination with sensory experiences
- Contribute to distractibility, difficulty in attending to tasks
- May lead to avoidance behaviors
- May lead to sensory seeking behavior
- May impact learning, social interactions, behavior



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# Co-occurring Diagnosis



- Depression
- Anxiety
- Obsessive Compulsive Disorder
- Intellectual Disability
- Sleep disorders
- Gastrointestinal issues
- Tics
- Eating Disorders
- Substance Abuse
- Communication Disorders ( Echolalia, Apraxia)
- Seizures



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# Co-occurring Diagnosis



- **Intellectual disability**

No intellectual disability in 58% boys (62% have ID), 42% girls (CDC, 2007)

Earlier studies reported 16-30% with no intellectual disability

- **Seizures**

Approximately 1 in 4 individuals develop seizures

- **Genetic syndromes**

Fragile X syndrome (25-67% of males with FXS have autistic behaviors or meet criteria), tuberous sclerosis (17-64%), Down syndrome (6-7%)

- **Mental health conditions**

Phobias, obsessive compulsive disorder, attention deficit hyperactivity disorder, depression, anxiety



# What to look for?



ASD impacts three main areas of daily functioning: communication, socialization, and behavior.

## Communication/Language Skills

- Social Interaction
- Repetitive Behaviors & Restricted Interests



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# Red Flags for Autism



- Child does not babble or coo by 12 months
- Child does not gesture (point, wave, grab) by 12 months
- Child does not say single words by 16 months
- Child does not use 2 word phrases on his own by 24 months
- Child may lose language or social skills after having acquired them



# Treatments for ASD



- Pharmacological- treats symptoms
- Biomedical
- Evidenced Based Practices
- Nutritionist
- Occupational therapy, Sensory diet
- Physical therapy
- Behavior Therapies
- Speech Therapy



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# ACT Early CDC



- **Developmental Milestones Checklist**

- Social/Emotional

Begins to smile at people

Can briefly calm himself (may bring hands to mouth and suck on hand)

Tries to look at parent

- <http://www.cdc.gov/actearly>

- <http://firstwords.fsu.edu/>



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# National Resources



- North Carolina Chapel Hill The National Professional Development Center on ASD  
<http://autismpdc.fpg.unc.edu/>
- AIM (Autism Internet Modules)  
<http://www.autisminternetmodules.org>
- Autism Society of America
- National Dissemination Center for Children with Disabilities <http://nichcy.org/>
- First Signs [www.firstsigns.org](http://www.firstsigns.org)
- Centers for Disease Control “Baby Steps: Learn the Signs. Act Early”



<http://www.cdc.gov/ncbddd/actearly/index.html>

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# Resources



- CDC – Tips for talking with Parents  
[http://www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/tipstalkingparents.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/tipstalkingparents.pdf)
- Autism Speaks Talking to Parents about Autism Kit  
<http://www.autismspeaks.org/what-autism/learn-signs/talking-parents-about-autism-action-kit>



# KY Medicaid Resources



- Department for Medicaid Services  
<http://chfs.ky.gov/dms>
- First Steps <http://chfs.ky.gov/dph/firststeps.htm>
- Home and Community Based Waiver  
<http://chfs.ky.gov/dms/hcb.htm>
- Supports for Community Living Waiver  
<http://dbhdid.ky.gov/ddid/scl>
- Michelle P Waiver  
<http://chfs.ky.gov/dms/mpw.htm>



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# KY Resources



- Commission for Children with Special Health Care Needs [chfs.ky.gov/ccshcn](http://chfs.ky.gov/ccshcn)
- Department of Behavioral Health Developmental and Intellectual Disabilities <http://dbhdid.ky.gov/kdbhdid/>
- Commonwealth Council on Developmental Disabilities [www.kyccdd.com](http://www.kyccdd.com)
- **University of Louisville** Autism Center <http://louisville.edu/education/kyautismtraining/>
- **University of Kentucky** Human Development Institute <https://www.hdi.uky.edu/>
- **Western Kentucky University** Kelly Autism Program [www.wku.edu/kellyautismprogram](http://www.wku.edu/kellyautismprogram)
- **Eastern Kentucky University** Psychology Dept. <http://psychology.eku.edu/psychology-clinic>



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