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Objectives
- Identify typical communication, social-emotional, and behavioral milestones in early childhood
- Identify early indicators/“red flags” for possible Autism Spectrum Disorders (ASD) and other developmental disabilities (DD) in young children

Objectives
- Discuss most appropriate screening and assessment measures to administer to young children at-risk for ASD/DD
- Outline American Academy of Pediatrics (AAP) and other professional recommendations for screening and multi-disciplinary diagnosis of young children with ASD

Objectives
- Identify and locate information and resources through the “Learn the Signs, Act Early” campaign and other dissemination sites
- Understand critical elements of intervention for young children at risk for ASD/DDS to increase appropriate referrals
Objectives

• Identify Alabama specific resources for screening, evaluation, and intervention for children with suspected ASD/DD

Commercial Interests Disclosure

• Sarah Elizabeth O’Kelley, Ph.D.
  – I have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this CME activity

Commercial Interests Disclosure

– I do not intend to discuss any unapproved or investigative use of a commercial product/devise in my presentation

Commercial Interests Disclosure

• Angela Barber, PhD, CCC-SLP
  – I have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this CME activity

Overview of Developmental Milestones and Early Indicators of ASD and Other DD
How Do We Improve Early Recognition?

- Know what skills and behaviors should be present
  - Typical developmental milestones
  - Range of possibilities at certain ages
  - When something is a delay

How Do We Improve Early Recognition?

- Know what skills and behaviors are unusual
  - Delays in expected skills
  - Presence of unexpected skills or behaviors

What Is ASD?

Autism Spectrum Disorders (Pervasive Developmental Disorders)

- Autism
- Asperger's Disorder
- PDD-NOS
- Rett's Disorder
- Childhood Disintegrative Disorder

Prevalence of ASD

- 1 in 88 children has an autism spectrum disorder in the United States (CDC, 2012)
  - 1 in 210 children has an autism spectrum disorder in Alabama

- Boys: 1 in 54
  - 1 in 123 in Alabama
- Girls: 1 in 252
  - 1 in 909 in Alabama

Prevalence highlights the need for standard, effective surveillance and screening procedures beginning early in development.
Impaired Communication Skills

- Delayed / Absent Spoken Language
  - Not compensated for by gesture or mime (1-3 words by 12 months, 2 word phrases by 22 months)

- Integrate eye contact, gestures, and vocalizations (12-18 months)
- Orient to name (9-12 months)
- Communicate for the function of joint attention or social interaction

- Stereotyped, Repetitive, Idiosyncratic Language
  - Echolalia, jargon, pronoun reversal, unusual pitch
**Impaired Communication Skills**

- Difficulty Initiating and Sustaining Conversation (conversational turn-taking 9-12 months)
  - Monologues, inability to answer questions

**Impairments in Social Interaction**

- Impairments in use of nonverbal behaviors to regulate social interaction and communication
  - Less likely to:
    - Look at others (intense interest in faces from first few months of life; 9 months looks to see if parent watching)

**Impairments in Social Interaction**

- Use gestures to communicate/interact with others (pointing and other gestures by 12 months)

**Impairments in Social Interaction**

- Lack of Seeking to Share Enjoyment and Interests
  - Less likely to:
    - Share interest (showing at 10-12 months)
    - Share affect such as enjoyment / excitement / pride

**Impairments in Social Interaction**

- Repeat actions gaining attention / laughter (9-12 months)
- Look at what others are looking at (12 months)
- Direct the attention of others (using gestures 12 months)

**Impairments in Social Interaction**

- Lack of Social / Emotional Reciprocity
  - Less likely to:
    - Engage in reciprocal, back-and-forth play (early simple play with parents by 12 months; peers 30-36 months)
Impairments in Social Interaction

- Smile back at others when they smile (4 months)
- Imitate others (facial expressions, actions, sounds 4-8 months; more complex imitation 12-18 months)
- Turn when name called (9-12 months)

Impairments in Social Interaction

- Failure to Develop Developmentally Appropriate Peer Relationships
  - Less likely to:
    - Show interest in other children by watching or proximity seeking (infant to infant interaction 6-9 months)
    - Engage in Parallel play (18-24 months)

Restricted and Repetitive Behaviors and Interests

- Stereotyped and Repetitive Motor Mannerisms
  - More likely to:
    - Engage in hand/finger or whole-body movements such as hand flapping, finger flicking, rocking

Restricted and Repetitive Behaviors and Interests

- Preoccupation with Parts of Objects
  - More likely to:
    - Line up toys / objects
    - Display interest in parts of toys
    - Engage in repetitive movements with objects
    - Heightened interest in sensory aspects

Restricted Repertoire of Activity and Interests

"Repetitive behaviors stand on the opposite end of the spectrum to true exploratory behavior. The need for sameness and for engaging in stereotypes often interferes with true exploration and learning in children with autism."

  – Grados and McCarthy, 2000

Restricted and Repetitive Behaviors and Interests

- Preoccupation with Particular Activity or Topic
  - Unusual in intensity or focus
- Inflexible Adherence to Routines or Rituals
  - Lining up toys, same route to school, verbal rituals
ASD vs. Developmental Delay/Intellectual Disability

Autism and Communication Disorders: Similarities and Differences
- Similarities
  - Delays in babbling
  - Delays or lack of spoken language
  - Limited speech
  - Limited vocabulary and grammar
  - Delayed symbolic play

- Specific to ASD
  - Greater deficits in social and non-verbal communication
    - Pointing, eye contact, imitation
    - Less spontaneous chatting

What Is Our Current Understanding of ASD?

Autism and Communication Disorders: Similarities and Differences
- More deviant language
  - Echolalia, pronoun reversal
  - Fewer articulation problems

Etiology of Autism
- Genetic studies
  - Frequency of autism in siblings:
    - Up to 20%
  - Concordance rate:
    - Monozygotic twins 36-91%
    - Dizygotic 0-5%
Etiology of Autism

• Current research has identified a number of areas of interest, but the heterogeneity of the disorder and symptom presentation makes this quite a task.

There exists significant heterogeneity not only in the genes involved, but also in the mode of inheritance of ASD. In some individuals, a single major gene may interact with environmental or other common genetic factors, and in others, multiple common or rare genetic factors may interact, with or without environmental or epigenetic factors to cause an ASD.”

- Geschwind, 2008

Etiology of Autism

• Prenatal and Perinatal Factors
  – Associated with developmental delay more than autism
• Immunizations
  – Research has not supported a link between autism and the MMR vaccine or thimerisol

Etiology of Autism

• Neuroanatomical Findings
  – A mixture of both “too much” and “too little” neuronal development
  • Increased brain volume
  • Cerebellum hypoplasia
  • Limbic system: reduced cell size and increased cell density

Etiology of Autism

What Does ASD Look Like in Young Children?
9 ASD Red Flags
- Impairment in Social Interaction
  - Lack of appropriate gaze
  - Lack of warm, joyful expressions
  - Lack of sharing interest or enjoyment
  - Lack of response to name

9 ASD Red Flags
- Impairment in Communication
  - Lack of showing
  - Lack of coordination of nonverbal communication
  - Unusual prosody

9 ASD Red Flags
- Repetitive Behavior and Restricted Interests
  - Repetitive movements with objects
  - Repetitive movements or posturing of body

4 ASD and DD Red Flags
- Impairment in Communication
  - Lack of pointing
  - Lack of playing with a variety of toys
  - Lack of response to contextual cues
  - Lack of communicative vocalizations with consonants

When Do Symptoms of ASD Present in Young Children?
- When compared to children with typical development parents of children with ASD noticed differences as early as:
  - 3-6 months for social interaction
  - 10-12 months for communication
  - 10-12 months for repetitive behavior

When Do Symptoms of ASD Present in Young Children?
- When compared to children with developmental delay, parents of children with ASD noticed differences as early as:
  - 13-15 months for social interaction
  - 19-21 months for communication
  - 16-18 months for repetitive behavior

References: Werner, Dawson, Munson, and Osterling, 2005
How Do Symptoms of ASD Present in Young Children?

- Social – Communication Skills
  - Decreased eye gaze
  - Lack of joint or shared attention
  - Decreased social or reciprocal smiling

- Inconsistent response or orienting to name
  - May respond to other sound

- Low use of gestures
  - Pointing
  - Low social interest

- Regression or loss of social-emotional responsivity
  - Limited expression of positive emotions
  - Limited integration of eye gaze, facial expression, gesture, and vocalization to communicate

- Language Skills
  - Delayed babbling
  - Lack of turn-taking in babbling
  - Repetitive or odd language
  - Regression or loss of first words
  - Abnormal vocal quality/tone

- Play Skills
  - Reduced imitation of actions with objects
  - Unusual and/or repetitive play with toys and objects
  - Unusual visual response and/or excessive visual exploration of objects

- Motor and Repetitive Behaviors
  - Repetitive and/or unusual motor mannerisms
  - Decreased level of activity and/or delayed fine and gross motor skills
  - Under- or over-reactivity to sensory stimulation
  - Visual, tactile, auditory
How Do Symptoms of ASD Present in Young Children?

• Other behaviors
  – Regression or loss of communication and/or social skills
  – Disrupted sleep, eating, and attention for age

Video Vignettes

• What red flags do you see?
• More clips available at:
  – www.autismspeaks.org

Appropriate Screening and Assessment Measures for Young Children At-Risk for ASD/DD

When Do ASD Symptoms Appear?

• Reliable diagnosis can be made by an experienced professional at 18-24 months
  – Of children diagnosed at 2 years of age:
    • 88-100% still on the spectrum at 3 years

When Do ASD Symptoms Appear?

• Over 85% still on the spectrum at 4 years
When Do ASD Symptoms Appear?

- Often parents report that they did not begin to notice symptoms until 24 months, but they later realize that behavioral abnormalities were present much earlier further highlighting the importance of routine screenings (Werner, 2005).

Definitions (AAP, 2006)

- Developmental surveillance
  - “A flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems”

- Developmental screening
  - “The administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder”
  - Not diagnostic!

- Developmental evaluation
  - “Aimed at identifying the specific developmental disorder or disorders affecting the child”

Why Screen?

- Concerns child may be deaf or have a hearing impairment
- Concerns over their child’s lack of language development
- Concerns they may have done something wrong as a parent
- Left the child during a trip, moved
Diagnostic Process for Parents

- Decision to take the child in for a medical “test” to determine what is wrong

Delays in Early Recognition and Referral

- Most parents suspect that something is “wrong” by 18 months and seek medical assistance by 2 years
  - Most diagnoses are not made until the child is 3-4 years of age

Delays in Early Recognition and Referral

- Children in rural areas diagnosed with autism spectrum disorders .4 years later than children in urban areas (Mandell, 2005)
  - Children in near-poor households diagnosed .9 years later than children in households with incomes at least 100% above the poverty level

Delays in Early Recognition and Referral: 2007-2008 Statewide Needs Assessment Team Findings

- Screening / Diagnosis
  - Only 7 ASD specific clinics, 2 interdisciplinary

Delays in Early Recognition and Referral

- For Alabama, median earliest age ASD was documented in their records: 5 years, 1 month
  - Children with more “classic” autism were diagnosed at 4 years, with other diagnoses between 5 and nearly 7 years of age
  - Later than the national average

- Alabama children wait almost 2 years longer than the national average to obtain a diagnosis
- Lack of professionals specifically trained in diagnosis and rule out of ASD
- Inconsistent early screening
Early Identification of ASD Is Critical

- Earlier identification leads to earlier intervention
- At least 2 years of intervention during preschool years leads to:
  - Increased language development
  - Higher IQ
  - Placement in regular education classroom

How Often Do Pediatricians Use Developmental Screening Tools?

- Red flags may not be easily observed in pediatric offices, compromising the efficacy of surveillance alone
  - In a survey of 646 general pediatricians, only 23% always or almost always used standardized screening instruments in their practice (Sand et al., 2005)

How Often Do Pediatricians Use Developmental Screening Tools?

- 71% always or almost always relied on non-standardized methods to detect developmental problems in 0-3 year old patients (Sand et al., 2005)

Impact of Developmental Screening

- After implementation of the ASQ and Pediatric Developmental Impression, referral rates to early intervention for children with developmental delay increased by 224% (Hix-Small et al., 2007)

Impact of Developmental Screening

- Referral rates to early intervention for children with developmental delay increased from 2-4% to 7% after implementing a screening schedule, in which the ASQ was completed at 6, 12, 24, 36, and 48 months of age (Pelletier & Abrams, 2002)

Earlier Autism Screening Shows Promise

- Brief parent questionnaire enables pediatricians to screen for autism at one year well baby check-up
Practice Parameters for Screening
- Absolute indications for immediate further evaluation:
  - No babbling by 12 months
  - No gesturing by 12 months
  - No single words by 16 months

Strategies for Monitoring and Responding to ASD in Office
- Assess social, communication, and play skills
  - Discussion and observation
- Obtain information about behaviors in multiple settings
  - How does s/he behave in daycare or play groups versus home?

Strategies for Monitoring and Responding to ASD in Office
- Refer for comprehensive audiology evaluation
- If concerns persist, refer for early intervention and / or ASD-specific evaluation
- Provide support for caregivers

Levels of Early Screening for ASD
- Step 1: Routine Developmental Surveillance
  - Immediate further developmental evaluation if:
    - No babbling, pointing, gestures at 12 months
    - No single words at 16 months
### Levels of Early Screening for ASD

- No spontaneous, non-echoed two-word phrases by 24 months
- Any loss of language or social skills at any age

### Levels of Early Screening for ASD

- Closer monitoring if:
  - Family history of ASD
  - Parental concerns
  - Not meeting developmental milestones, especially in social and communication development

### Levels of Early Screening for ASD

- Step 2: Screening Specifically for ASD
  - If concerns arise during the routine developmental screening, the following recommendations are made for screening specifically for ASD:
    - Completion of an ASD-specific screening measure
    - Medical evaluation to rule out hearing loss, visual impairment, and/or other physiological anomalies

### Levels of Early Screening for ASD

- Step 3: Diagnostic Evaluation
  - If concerns arise during the screening for ASD symptoms (i.e., significant items are endorsed that suggest a possibility of ASD), a referral for a comprehensive ASD diagnostic evaluation is recommended

### Full Diagnostic Evaluation for ASD

- Rule out sensory impairment
  - Vision and hearing
- Extensive interview with caregivers
  - Autism Diagnostic Interview-Revised
  - Clinical interview
### Full Diagnostic Evaluation for ASD

- Structured observation / interaction
  - Autism Diagnostic Observation Schedule
- Rating scale / checklist
  - Childhood Autism Rating Scale-2
  - Social Responsiveness Scale
- Rule out other disorders

### Additional Evaluations and Assessments

- Must have:
  - Cognitive / intellectual
  - Language and communication
  - Adaptive
  - Broad band behavior ratings

### Additional Evaluations and Assessments

- Exploration of strengths and weaknesses
- Additional measures may include:
  - Achievement
    - Individual or group
  - Motor
  - Nutrition

### Surveillance Questions

1. Does the child turn when his / her name is called?
2. Does the child follow another person’s point to locate an object across the room?
3. Does the child use a showing gesture to share objects with other people?  
   Barber & Klinger, 2011

### Surveillance Questions

4. Does the child smile and make eye contact when playing peek-a-boo or other games?
5. Does the child use words and phrases to communicate?  
   Barber & Klinger, 2011

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- Osterling and Dawson, 1995; Werner, Dawson, Munson, & Osterling, 2005; Wetherby et al., 2004

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- Barber & Klinger, 2011
Autism Specific Screeners

M-CHAT
- Modified Checklist for Autism in Toddlers (M-CHAT) Robins, Fein, and Barton, 1999
- 23 Yes / No responses for children 18-30 months of age
- Can be scored in 5 minutes

M-CHAT
- Works best when the screener is combined with follow-up questions with family members
- Validate questions and conduct a hearing assessment as a first step

ESAC
- Detailed autism-specific parent report screening tool for children 12-36 months

ESAC
- The research version of the ESAC is a 47-item questionnaire that represents all three autism diagnostic domains of the DSM-IV
- Reminder: Not all children who fail the checklist will meet all criteria for diagnosis on the autism spectrum

Broadband Developmental Screeners
**Ages and Stages-3**
- The Ages and Stages Questionnaire-3rd Edition (ASQ-3), Squires et al., 2009
- 24-item broad-based measure of developmental milestones in infants and young children from 1-66 months of age

**CSBS-ITC**
- 6 months-24 months
- Measures symbolic, social, and speech skills across 24 questions

**Resources and Intervention for ASD/DD**

**Simultaneously Refer for Evaluation and Intervention!**
- Limited resources lead to longer waiting times for screening and diagnosis and intervention
- Recommendation is...
  - REFER FOR ASD-SPECIFIC INTERVENTION AS SOON AS A DIAGNOSIS OF ASD IS CONSIDERED!

**Current Evidence Base for Intervention with ASD**
- Evidence that intervention does cause change in symptoms and behaviors
- Not enough rigorous research
  - Few cross-program comparisons
  - Many programs / packages have many elements
Current Evidence Base for Intervention with ASD

- A great deal of research currently filling this gap

What Is Currently Evidence-based? According to the NPDC (2008)...

- Behavioral strategies (prompting, time delay, reinforcement, task analysis and chaining)
- Computer-aided instruction
- Differential reinforcement
- Discrete trial training
- Extinction
- Functional behavior assessment
- Functional communication training
- Naturalistic interventions
- Parent-implemented intervention
- Peer mediated instruction / intervention

What Is Currently Evidence-based?

- PECS
- Pivotal response training
- Response interruption / redirection
- Self-management
- Social narratives
- Social skills training groups
- Stimulus control / environmental modification
- Structured work systems
- Video modeling
- Visual supports
- VOCA/SGD (Speech generating devices)

Critical Elements of Effective Intervention

- Implementation as soon as an ASD diagnosis is seriously considered
- Implementation by highly trained staff who:
  - Have an understanding of the features of ASD

Critical Elements of Effective Intervention

- Have training and background in ASD-specific techniques of intervention
- Active engagement in planned programming for more than 25 hours per week, 12 months per year
- Systematic, planned, developmentally appropriate instruction

Critical Elements of Effective Intervention

- Working toward specific individualized goals and objectives
- Ongoing assessment of progress and adaptation of programming if adequate progress is not being attained
  - At least every 3 months
Critical Elements of Effective Intervention
• Individualized attention provided in frequent intervals

Critical Elements of Effective Intervention
• Inclusion with peers with typical development as appropriate
• Highly structured and supportive environment and routine
• Generalization of skills across environments and working in the natural environment

Critical Elements of Effective Intervention
• Family involvement and parent education
• Problem behaviors should be addressed in a positive manner and in context, with a focus on developing replacement behaviors

Interventions Should Focus on the Core Symptoms of ASD
• Increased spontaneous and functional communication
  – Functional, spontaneous communication
  – Receptive language

Interventions Should Focus on the Core Symptoms of ASD
• Increased age-appropriate social skills and social interactions and play skills
  – Imitation, joint attention, turn-taking, pretend play, peer interaction

Interventions Should Focus on the Core Symptoms of ASD
• Reduced time engaging in repetitive behaviors
  – Attention to the environment and response to appropriate motivators
Ongoing Reviews and Resources

- Ongoing literature reviews (available online)
  - National Professional Development Center on ASD
  - National Autism Center’s National Standards Project

Web-based training modules
- www.autisminternetmodules.org

What Is Happening in Alabama to Improve Early Identification and Intervention with ASD/DD?

Statewide Needs Assessment Team Findings (2007-08)
- Intervention
  - Poor screening / diagnosis are barriers to receiving intervention
  - Very few intervention options and even fewer are interdisciplinary

- Very little ASD specific intervention provided and most receive either nonspecific intervention or those without basis in evidence
- Intensity of intervention is less than 1/10th of that recommended for children with ASD

Progress: A 5-year Retrospective
- State Task Force
- Inter-agency Coordinating Council
  - www.autism.alabama.gov
- Statewide Work Groups focused on various aspects of improving understanding of ASD and related services
Progress: A 5-year Retrospective

- Developing Regional Networks
- 2012 ADDM Data
  - 4.8 per 1,000 for Alabama
- Median age of diagnosis:
  - 48 months for Autistic Disorder
  - Was 51 months in 2009 data, 66 months in 2006 data

Alabama Interagency Autism Coordinating Council: Planning for Regional Autism Centers

- Standards of care for screening, diagnosis, and intervention
- Work groups recommending minimum, best practice, and gold standard levels of practice (work in progress)
  - [www.autism.alabama.gov](http://www.autism.alabama.gov)

Act Early Alabama!

- Project leaders:
  - Sarah O'Kelley (UAB) and Melanie Jones (Autism Society)
  - Activities supported by funding from AUCD, CDC, AMCHP

Act Early Alabama!

- Objectives:
  - Increased awareness of early developmental milestones and ASD red flags
  - Increased referrals to sources of screening, evaluation, and intervention

Act Early Alabama!

- Coordinated efforts within the ASD and early childhood education communities
- Groups targeted:
  - Parents, caregivers, family members, health care professionals, early care and education, general public

Act Early Alabama Awareness and Training Initiative

- Activities include:
  - Bringing together stakeholders including representatives from state agencies, family members, and others to develop a state plan for information dissemination
  - Providing Act Early webinar for professionals across Alabama
Act Early Alabama Awareness and Training Initiative
– Producing Alabama specific awareness materials
– Developing Act Early Alabama website to direct caregivers and professionals to assessment and intervention resources
  • www.uab.edu/civitansparks/act-early-alabama (under construction)

Act Early Alabama Awareness and Training Initiative
– Develop a statewide network of Act Early trainers

“Learn the Signs. Act Early.”
• www.cdc.gov/actearly
• 1-800-CDC-INFO
• Primary audience:
  – All parents of children aged 4 and under

“Learn the Signs. Act Early.”
• Secondary audiences:
  – Early educators
  – Health care providers
• Materials available for download (English and Spanish)
  – Resource kits for parents, early educators, health care providers
  – Brochures

Online Tools and Resources
• Printable Milestone Checklists
• E-Cards
• Videos, PSAs
• Website linking instructions, badges, buttons
• Interactive Milestones Chart
Online Tools and Resources
- “If You’re Concerned…,” “What to say,” “While you wait”
- Positive Parenting Tips
- “Go Out and Play! Kit” for early educators

AAP Toolkits for Alabama
- Designed to support and guide management of children with ASD in the medical home
- Provides information on identification, referral, fact sheets, family handouts
  - Seizures, sleep
- Provided on CD-ROM

AAP Toolkits for Alabama
- Act Early Alabama team
  - Providing documents to complement this resource in an effort to be more state-specific and user-friendly

Alabama Resources: Child Find
- Birth to 2 years, 11 months
  - Early intervention
  - 1 – 800 – 543 – 3098

Alabama Resources: Child Find
- 3 years old and older
  - Local school system
  - 1 – 800 – 392 – 8020
  - Call the school, Board of Education, or the State Department of Education

Alabama ASD Sites
- www.autism-alabama.org
  - Website for the Autism Society of Alabama, a statewide education and advocacy organization
  - Maintains list of resources for individuals with ASD and their families across the state
### Alabama ASD Sites

- [www.autism.alabama.gov](http://www.autism.alabama.gov)
  - Website for the [Alabama Interagency Autism Coordinating Council](http://www.autism.alabama.gov), with access to documents regarding standards of care and other initiatives across the state

- [www.Alex.state.al.us/autismAL](http://www.Alex.state.al.us/autismAL)
  - Autism ALABAMA website compiling online training resources and information for educators and families in Alabama, offered through the Alabama Department of Education

- [www.al-autismproviders.net](http://www.al-autismproviders.net)
  - Alabama Autism Providers Network, promoting collaboration among service providers in Alabama and to promote best practice, standards and regulations to ensure that quality services are made available to people in Alabama with ASD and their families/caregivers

### Message for Frontline Providers in Alabama (YOU!)

- Physicians, nurses, early childcare providers, clinicians, teachers, and parents/caregivers are encouraged to be committed to identifying early red flags and to referring children for appropriate intervention services when a child deviates from a typical developmental path or when ASD is first suspected

### Contact Information

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*Thank you for your participation!*

*Please contact us with your questions, and we appreciate your willingness to join in the efforts to “Act Early Alabama!”*