Learn the Signs. Act Early.

It's time to change how we view a child’s growth.
Campaign Founding Partners

- American Academy of Pediatrics (AAP)
- Autism Society of America (ASA)
- Autism Speaks
- First Signs
- Organization for Autism Research (OAR)

...and many community champions!!!
Mission

Every child reaches his or her full potential

Learn the Signs. Act Early.
Early Research: Health Care Providers

- Less than one-third (27%) believed their colleagues are well-informed about developmental disorders
- 42% did not know autism can be diagnosed as early as 18 months
- 59% said they do not have resources needed to educate parents

Learn the Signs. Act Early.
Early Research: Parents

- Lacked knowledge about
  - cognitive, emotional, and social development
  - developmental delays

- Recommend that efforts communicate urgency of acting early when there is a concern about developmental delay

- Clear consensus to avoid using language such as “autism” and “ASD”
Campaign Objectives

- Increase **AWARENESS** of developmental milestones and early warning signs
- Increase **KNOWLEDGE** in the benefits of early action and early intervention
- Increase parent-provider **DIALOGUE** on the topic of developmental milestones and disorders
- Increase **EARLY ACTION** on childhood developmental disorders
Target Audiences

- Health Care Professionals (HCPs)
  - Pediatricians, family physicians, physician assistants, nurses
- Parents of Young Children
  - Ages 4 and younger
- Early Educators (EEs)
  - Day care providers, preschool teachers, etc.
Outreach to Health Care Professionals
Materials

- Resource Kit encourages conversation between professionals and parents
  - “How to Talk to Your Doctor” informational cards
  - Fact sheet series on milestones, developmental disorders and resources

Learn the Signs. Act Early.
Outreach to Parents

Learn the Signs. Act Early.
Outreach to Parents

• PSAs for TV, radio, and print
• Media outreach
• Parent Resource Kit (growth chart, fact sheets, informational card)
Partners Reach Parents

Learn More About Early Childhood Developmental Milestones

This campaign is designed to educate parents about childhood development, including the warning signs of developmental delay and the important role parents can play in their child's development. Parents are encouraged to "Learn the Signs. Act Early." to help prevent delays in their child's development.

Learn the Signs. Act Early.
Campaign Goes BIG!

Learn the Signs. Act Early.
Hispanic Outreach

- All materials available in Spanish
- Call center equipped for Spanish speakers
- Web site in Spanish – www.cdc.gov/pronto
- Print and radio media reaches Spanish-language populations

Learn the Signs. Act Early.
Outreach to Early Educators
Outreach to EEs

• Launched in Nov. 2006
• What we’ve learned so far:
  – EEs recognize their role in early identification
  – EEs consider themselves advocates for the children in their care
  – Materials to bridge the conversation with parents are critical

Learn the Signs. Act Early.
Campaign Activities
HCP Outreach Activities

- Reached more than 5 million HCPs through e-cards and newsletter articles
- Reached more than 80,000 HCPs through conferences
- Distributed nearly 27,000 Resource Kits
- Recorded more than 45,000 materials downloaded and 104,000 page views of HCP materials
- State and local outreach through professional associations
- Public health outreach

Learn the Signs. Act Early.
Parent Outreach Activities

• News media coverage in national outlets: “Good Morning America,” Newsweek, Child, Parenting, Parents, MSNBC, CNBC, AP, NY Times, LA Times…reached an estimated 4 million people

• Distributed nearly 44,000 Parent Kits

• More than 85,000 materials for parents downloaded from website

• More than 2.26 million web pages viewed; nearly 683,000 unique visitors
Early Educator Outreach Activities

• Partnered with:
  – National Association for the Education of Young Children
  – Early Head Start
  – National Association of Child Care Resource and Referral Agencies
  – National Association of Child Care Providers

• Distributed nearly 6,000 EE Kits

• Recorded more than 25,000 pages views of EE resources and 3,100 materials downloaded from website

Learn the Signs. Act Early.
Campaign Effects

Learn the Signs. Act Early.
Surveys

- HealthStyles and DocStyles
- Panel surveys (mail and web-based)
- Weighted to U.S. population
- Sample sizes –
  - HealthStyles (n=>2000 adults; >400 parents of children under age 4)
  - DocStyles (n=765; Peds n= 250 GP/FP n=515)
Increase AWARENESS of developmental milestones and early warning signs

Key measures we’re monitoring:

• Parent report of looking for milestones
• Knowledge of “warning sign” behavior
• Physician report of parent knowledge
• When to look for early warning signs
• Who can best see the “signs”
Increase **KNOWLEDGE** in the benefits of early action and early intervention

Key measures we’re monitoring:

• Beliefs about helpfulness of early intervention

• Best time to help children
Increase parent-provider DIALOGUE on the topic of developmental milestones and disorders

Key measures we’re monitoring:

- Parent report of HCP’s asking about child development
- Parent report of information seeking with HCP
- Provider report of parental information seeking
- Provider report of adequate resources for educating parents

Learn the Signs. Act Early.
Increase EARLY ACTION on childhood developmental disorders

Key measures we’re monitoring:

• Parent and provider reports of “wait and see” approach
• Awareness of referral resources
• Best time to diagnose autism
• Difficulty of diagnosing autism

Learn the Signs. Act Early.
Good news...

Parents
- More are looking for developmental milestones
- More know behaviors that suggest autism/early signs

HCPs
- Fewer are recommending “wait and see” approach
- More state they have resources to educate parents
- More have favorable views of early intervention

Learn the Signs. Act Early.
Good news...

Both parents and HCPs

• More know the early warning signs of autism
• Know that earlier identification/help is better (under 2 years old)
• More report talking with each other (dialogue)

Learn the Signs. Act Early.
Areas needing attention

Parents

• Need more encouragement to ask questions about child development
• Need to know what to do if a physician says “wait and see”
• Need to understand how difficult diagnosis is
Areas needing attention

HCPs

• FP/GP need to know more about referral resources and that diagnosis can occur as early as 18 months

• Need to use standardized screening tools
Act Early

Need more

– Clarity
– Specificity
– Concordance in expectations

Learn the Signs. Act Early.
Act Early

• Screening, Identification, Referral, Diagnosis, Eligibility determinations
• Internal and external discussions
• Cooperative Agreements--with AUCD & AAP
  – AUCD Regional Meetings
  – AAP Screening projects

Learn the Signs. Act Early.
How to Get Involved

• Promote the campaign’s resources among faculty and trainees
• Distribute materials in your community
• Participate in grassroots outreach efforts--Speak about the campaign
• Provide ideas about Act Early messages
Thank you!

www.cdc.gov/actearly

gpeacock@cdc.gov

kkilker@cdc.gov
Learn the Signs. Act Early.
Learn the Signs. Act Early.
## Baseline to 2007 Comparison

<table>
<thead>
<tr>
<th>Parents of Young Children</th>
<th>2004/2005</th>
<th>2007</th>
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<tbody>
<tr>
<td>Know which behaviors suggest that a child may have autism</td>
<td>37%</td>
<td>52%</td>
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<td>During last well-child visit, a doctor or nurse asked about child’s development</td>
<td>73%</td>
<td>81%</td>
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<td>Asked doctor or nurse at last well-child visit about how their child should play, act, speak, or learn</td>
<td>36%</td>
<td>45%</td>
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<td>Report that the best time to get help for children with autism is before 2 years of age</td>
<td>22%</td>
<td>42%</td>
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<td>Agree that a child with autism can be diagnosed as early as 18 months of age</td>
<td>71%</td>
<td>80%</td>
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<tr>
<td>Have the resources they need to teach parents about tracking their child’s cognitive, social, and physical development</td>
<td>49%</td>
<td>77%</td>
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<td>Parents of their patients know the early warning signs of developmental disabilities such as autism</td>
<td>17%</td>
<td>28%</td>
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<th>Family Physicians/General Practitioners</th>
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<th>2007</th>
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<td>Agree that a child with autism can be diagnosed as early as 18 months of age</td>
<td>44%</td>
<td>48%</td>
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<td>Have the resources they need to teach parents about tracking their child’s cognitive, social, and physical development</td>
<td>32%</td>
<td>47%</td>
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Learn the Signs. Act Early.
I have heard of CDC’s campaign “Learn the Signs. Act Early” (% agree/2007)
I look for the developmental milestones my child should be reaching in terms of how he plays, acts, speaks, and learns.
Which behavior most suggests that a child may have autism

- Will not share toys
- Colicky for 6 months
- Not using words by 2 or losing words
- Impulsive
- Don’t know

Year-wise distribution:
- 2004
- 2006
- 2007
Parents of my pediatric patients know the early signs of developmental disabilities such as autism (% agree)
Who can best see the early signs of autism

![Bar chart showing the percentage of respondents for different roles over three years (2004, 2006, 2007). The roles include Parents, School Teachers, Daycare Providers, Medical Professionals, Other, and Don't Know. The chart indicates that Parents consistently have the highest percentage, followed by School Teachers and Medical Professionals, with the lowest percentage for Don't Know.]
Early intervention can help children with developmental delays like autism improve considerably.
Early intervention can help children with developmental delays like autism improve considerably (% agree)

2004
2007

Pediatricians
FP/GP
Best time to get help for children with autism

![Bar chart showing the best time to get help for children with autism for different years: 2004, 2006, and 2007. The chart compares the percentage of responses before 6 months, before 2 years, before kindergarten, and don't know. The data shows a trend with a peak around 2007 for before 6 months and before 2 years.]
During my child’s last well-child visit, the nurse or doctor asked me about how my child plays, acts, speaks or learns.
During my child’s last well-child visit, I asked the nurse or doctor for information about how my child should play, act, speak, or learn.
The number of patients who ask questions about autism has been increasing every year (% agree)
I have the resources necessary to educate parents about monitoring their child’s cognitive, social and physical development (% agree)
If a doctor tells a worried parent to wait and see if a child outgrows a development problem, what do you think the parent should do?
When parents of my pediatric patients first tell me they are concerned about their child’s development, I typically recommend they wait for a few months or so to see if the problem resolved during that time (% agree)
I’m aware of resources available for referrals and treatment for developmental delays (% agree)

Pediatricians FP/GP

2004 2007

54
A child with autism can be diagnosed as early as the age of 18 months (% agree)
Correctly recognizing and diagnosing autism early on can be extremely difficult.
Parents who suspect their child may have autism can seek early intervention for their child without a doctor’s referral.
I believe most health insurance plans cover treatment for children with autism.
Health insurance plans should cover treatment for children with autism

Parents
When I suspect autism in a patient I usually refer them to...

- Developmental pediatrician
- Neurologist
- Child psychiatrist
- Child psychologist
- Private speech therapist
- Local private autism school/center
- Parent advocacy group
- Local school district
- Other
At what point do you refer children to early intervention?

- Never—I don't know what early intervention is
- Never—I don't refer to early intervention
- After consultation with a specialist
- After determining specific etiology of developmental delay
- After identification of developmental delay on a standardized screen
- Suspicion of a developmental delay

- [FP/GP] 
- [Pediatrician]

0 20 40 60 80 100
When I refer a child to early intervention (Part C, Birth to 3 services), I usually...

- I don't refer to Part C Birth to 3 state services
- Find out from the parent that services were not available
- Get no information from the early intervention provider
- Get limited information from the early intervention provider
- Get detailed information from the early intervention provider
When I refer a child to early intervention (Part C, Birth to 3 services), I usually…

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- Get detailed information from the early intervention provider

![Bar chart showing referrals and information sources.](chart.png)
What might prevent you from referring children with developmental delays to the Part C Birth to Three services offered by the state?

- Don't know the contact information
- Don't get a response when I refer
- Can't reach the program to make the referral
- Process for referral is too difficult
- Cost of program limits patient use
- It's not effective
- Need to know diagnosis before I refer
- Other

**FP/GP**

**Pediatrician**
Which of the following have you heard are effective for treating children with autism

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Parents (%)</th>
<th>FP/GP (%)</th>
<th>Ped (%)</th>
<th>Therapy</th>
<th>Parents (%)</th>
<th>FP/GP (%)</th>
<th>Ped (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PECS</td>
<td>3</td>
<td>2.7</td>
<td>6.8</td>
<td>Applied behavioral analysis</td>
<td>8</td>
<td>16.5</td>
<td>39.2</td>
</tr>
<tr>
<td>TEACCH</td>
<td>1</td>
<td>5.4</td>
<td>14.4</td>
<td>Gluten-free, casein-free diet</td>
<td>6</td>
<td>15.9</td>
<td>18.0</td>
</tr>
<tr>
<td>Floortime</td>
<td>4</td>
<td>13.2</td>
<td>22.0</td>
<td>Relationship development intervention</td>
<td>6</td>
<td>16.9</td>
<td>18.4</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>13</td>
<td>47.4</td>
<td>78.8</td>
<td>Drug therapy</td>
<td>5</td>
<td>7.4</td>
<td>20.0</td>
</tr>
<tr>
<td>Chelation therapy</td>
<td>2</td>
<td>4.7</td>
<td>7.6</td>
<td>Hyperbaric oxygen therapy</td>
<td>1</td>
<td>2.3</td>
<td>3.6</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>19</td>
<td>47.8</td>
<td>76.8</td>
<td>None—haven’t heard of these</td>
<td>38</td>
<td>11.7</td>
<td>0.4</td>
</tr>
<tr>
<td>Verbal behavior intervention</td>
<td>10</td>
<td>25.2</td>
<td>30.0</td>
<td>None—have heard but don’t know about effectiveness</td>
<td>20</td>
<td>17.9</td>
<td>6.8</td>
</tr>
<tr>
<td>Sensory integration therapy</td>
<td>22</td>
<td>43.5</td>
<td>67.2</td>
<td>None—don’t think any are effective</td>
<td>4</td>
<td>2.1</td>
<td>2.0 65</td>
</tr>
</tbody>
</table>
Exploring “Act Early”

Measures we explored:

– Health insurance coverage
– Physician referral sources
– Parent and physician interaction with early intervention
– Knowledge about autism therapies