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
Early Research: Parents

- Lacked knowledge about
  - Cognitive, emotional, and social development
  - Developmental delays
- Recommend efforts communicate the urgency of acting early when there is a concern about developmental delay
- Clear consensus to avoid using language such as “autism” and “ASD” in materials designed to reach all parents of young children

Learn the Signs. Act Early.
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

Learn the Signs. Act Early.
Target Audiences

- Health Care Professionals (HCPs)
  - Pediatricians, family physicians, physician assistants, nurse practitioners, nurses, and others
- Parents of Young Children
  - Ages 4 and younger
- Early Educators (EEs)
  - Preschool teachers, day care providers, and others

Learn the Signs. Act Early.
Health Care Professionals
Equipping HCPs

- **Resource Kit**
  - “How to Talk to Your Doctor” informational cards
  - Fact sheet series on milestones, developmental disorders and resources
  - Materials for waiting rooms and exam rooms
- **Website Resources**
  - CDC and AAP screening guidelines
  - Coding information
  - AAP Autism Toolkit

Learn the Signs. Act Early.
Reaching HCPs Through Materials and the Web

- More than 31,000 resource kits distributed
- More than 52,000 materials downloaded
- More than 116,000 page views of health care professional materials
Reaching HCPs Through Professional Organizations

- Collaborations with associations including American Academy of Pediatrics, American Academy of Family Physicians and Office of Minority Health
  - Exhibits and presentations at 47 conferences
  - E-cards and newsletters to more than 5 million
- State and local professional associations
- Public health centers in both urban and rural areas

Learn the Signs. Act Early.
Health Care Professional Results
Have Heard of “Learn the Signs. Act Early.”

Learn the Signs. Act Early.
## Baseline to 2007 Comparison

<table>
<thead>
<tr>
<th></th>
<th>Pediatricians</th>
<th>Family Physician/General Practitioner</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2004/2005</strong></td>
<td><strong>2007</strong></td>
<td></td>
</tr>
<tr>
<td>Agree that a child with autism can be diagnosed as early as 18 months of age</td>
<td>71%</td>
<td>80%</td>
</tr>
<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>
</tr>
<tr>
<td>Parents of their patients know the early warning signs of developmental disabilities</td>
<td>17%</td>
<td>28%</td>
</tr>
<tr>
<td><strong>2004/2005</strong></td>
<td><strong>2007</strong></td>
<td></td>
</tr>
<tr>
<td>Agree that a child with autism can be diagnosed as early as 18 months of age</td>
<td>44%</td>
<td>48%</td>
</tr>
<tr>
<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>
</tr>
</tbody>
</table>

*Learn the Signs. Act Early.*
Believe Early Intervention Can Help

Pediatricians

FP/GP

Learn the Signs. Act Early.
Knowledge of Resources for Referrals and Treatment

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatricians</td>
<td>89%</td>
<td>93%</td>
</tr>
<tr>
<td>FP/GP</td>
<td>68%</td>
<td>74%</td>
</tr>
</tbody>
</table>

Learn the Signs. Act Early.
Typically Recommend Concerned Parents “Wait and See”

**Pediatricians**
- 2004: 30%
- 2007: 19%

**FP/GP**
- 2004: 32%
- 2007: 22%

Learn the Signs. Act Early.
Parents

Learn the Signs. Act Early.
Educating Parents

• Parent resource kit
• Website with information and interactive tools
• Spanish-language resources, including materials, call center and website (www.cdc.gov/pronto)
• Public Service Announcements for TV, radio, and print

Learn the Signs. Act Early.
Reaching Parents Through Media

- Nearly 45 million impressions through broadcast, print, and online placements

<table>
<thead>
<tr>
<th>“Good Morning America”</th>
<th>MSNBC</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York Times</td>
<td>CNBC</td>
<td>Parenting</td>
</tr>
<tr>
<td>Los Angeles Times</td>
<td>AP</td>
<td>Child</td>
</tr>
</tbody>
</table>

- Television, radio, and print PSAs ran more than 2,300 times around the country

Learn the Signs. Act Early.
Reaching Parents Online

• More than 1.7 million web views of parent materials, 78,000 parent materials downloaded and 51,000 kits distributed
• Campaign PSA viewed more than 15,000 times on YouTube
• More than 1,000 consumers linked to the campaign through Wikipedia
• More than one million listeners reached through podcasts like MommyCast

Learn the Signs. Act Early.
Reaching Parents Where They Play

• Campaign messages on the Goodyear Blimp during national sporting events

• TV PSA on Astrovision in Times Square, reaching approximately 91 million

• Poster on Grey’s Anatomy for past three seasons

• Campaign promotions on FOX Sports during two televised NASCAR races

Learn the Signs. Act Early.
Reaching Hispanic and African-American Parents

• Hispanic
  – Partnered with the League of Latin American Citizens
  – Conducted media outreach targeting top Hispanic newspapers and national television programs

• African-American
  – Partnered with the Congressional Black Caucus
  – Conducted outreach to megachurches’ children’s ministries, preschools, and membership, reaching 30,000
  – Broadcast PSA on Daystar Television Network, reaching 128 million
Parent Results

Learn the Signs. Act Early.
34% of parents of young children have heard of “Learn the Signs. Act Early"
Look for Developmental Milestones

Learn the Signs. Act Early.
Knowledge of Behavior Suggesting Autism

- Will not share toys: 1% (2004), 0% (2006), 0% (2007)
- Colicky for 6 months: 1%, 1%, 1%
- Not using words by 2 or losing words: 52% (2004), 48% (2006), 37% (2007)
- Impulsive: 5%, 3%, 4%
- Don't know: 57%, 48%, 42%

Learn the Signs. Act Early.
Best Time to Get Help for Children with Autism

![Bar chart showing the best time to get help for children with Autism between 2004 and 2007.

- Don't Know: 49% in 2004, 42% in 2006, 33% in 2007.]

Learn the Signs. Act Early.
Who Can Best See Early Signs of Autism

Learn the Signs. Act Early.
Asked HCPs About Development

Learn the Signs. Act Early.
HCP Asked About Development

![Bar chart showing data]

Learn the Signs. Act Early.
What to Do If HCP Says “Wait and See”

- Wait 6 months
- Wait 1 year
- Take to another Dr.
- Enroll in Early Education
- Don’t Know

Learn the Signs. Act Early.
Equipping Early Educators

- **Resource Kit**
  - Growth chart, posters, flyers, and CD-ROM with fact sheets
  - Tips for talking with parents
- **Online Resources**
  - Information on child development
  - Interactive Milestones Checklist

Learn the Signs. Act Early.
Reaching EEs Through Professional Organizations

• 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
Reaching EEs Through Materials and the Web

- Reached more than 135,000 early educators through conferences
- Distributed nearly 15,000 kits
- Recorded more than 39,000 pages views of early educator resources and 5,700 materials downloaded from website

Learn the Signs. Act Early.
Campaign Evaluation

Learn the Signs. Act Early.

CDC
Good news...

- More parents look for developmental milestones and know behaviors that suggest early signs of autism
- More HCPs state they have resources to educate parents
- Fewer HCPs advocate a “wait and see” approach when they suspect a child of having a developmental delay

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

More parents and HCPs

• Know the early warning signs of autism
• Believe that early identification/intervention can help and the best time is for children 2 years old and younger
• Report asking talking with each other about child development

Learn the Signs. Act Early.
Opportunities to Continue Achieving the Campaign Mission

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
Opportunities to Continue Achieving the Campaign Mission

HCPs

- Family Physicians and General Practitioners need to know more about referral resources and that diagnosis can occur as early as 18 months

- Need to use standardized screening tools

Learn the Signs. Act Early.
Early Identification and Intervention

Learn the Signs. Act Early.

CDC
SAFER・HEALTHIER・PEOPLE®
Believe Early Intervention Can Help

Learn the Signs. Act Early.
When HCPs 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

Learn the Signs. Act Early.
Where HCPs Refer Children

- Developmental pediatrician: 55%
- Neurologist: 71%
- Parent advocacy group: 10%
- Local school district: 15%
- Local private autism school/center: 16%
- Private speech therapist: 12%
- Child psychologist: 16%
- Child psychiatrist: 16%
- Other: 4%
- FP/GP: Part C (Birth to 3) 52%
- Pediatrician: Part C (Birth to 3) 18%

Learn the Signs. Act Early.
What Happens After A Referral to Part C

- I don't refer to Part C Birth to 3 state services: 6% (FP/GP), 15% (Pediatrician)
- Find out from the parent that services were not available: 1% (FP/GP), 0% (Pediatrician)
- Get no information from the early intervention provider: 9% (FP/GP), 12% (Pediatrician)
- Get limited information from the early intervention provider: 32% (FP/GP), 36% (Pediatrician)
- Get detailed information from the early intervention provider: 43% (FP/GP), 47% (Pediatrician)

Learn the Signs. Act Early.
Reasons HCPs Do Not Refer to Part C

- Don't know the contact information: 48%
- Process for referral is too difficult: 18%
- Cost of program limits patient use: 15%
- Can't reach the program to make the referral: 16%
- Don't get a response when I refer: 17%
- Need to know diagnosis before I refer: 11%
- It's not effective: 1%
- Other: 46%

FP/GP Pediatrician
## What Parents and HCPS Believe Are Effective Treatments for ASDs

<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>3</td>
<td>7</td>
<td>Applied behavioral analysis</td>
<td>8</td>
<td>17</td>
<td>39</td>
</tr>
<tr>
<td>TEACCH</td>
<td>1</td>
<td>5</td>
<td>14</td>
<td>Gluten-free, casein-free diet</td>
<td>6</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>Floortime</td>
<td>4</td>
<td>13</td>
<td>22</td>
<td>Relationship development intervention</td>
<td>6</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>13</td>
<td>47</td>
<td>78</td>
<td>Drug therapy</td>
<td>5</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>Chelation therapy</td>
<td>2</td>
<td>5</td>
<td>8</td>
<td>Hyperbaric oxygen therapy</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>19</td>
<td>48</td>
<td>77</td>
<td>None—haven’t heard of these</td>
<td>38</td>
<td>12</td>
<td>0.4</td>
</tr>
<tr>
<td>Verbal behavior intervention</td>
<td>10</td>
<td>25</td>
<td>30</td>
<td>None—have heard but don’t know about effectiveness</td>
<td>20</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Sensory integration therapy</td>
<td>22</td>
<td>44</td>
<td>67</td>
<td>None—don’t think any are effective</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>
Parents’ Belief That They Can Self-Refer to Early Intervention

Learn the Signs. Act Early.
Parents’ Belief That Insurance Should Cover Treatment for ASDs

Learn the Signs. Act Early.
Parents’ Belief That Most Insurance Covers Treatment for ASDs

Learn the Signs. Act Early.
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

Learn the Signs. Act Early.
Thank you!
www.cdc.gov/actearly
kkilker@cdc.gov