Early Identification of Developmental Disabilities: Practical Tools

Rebecca B. Wolf, MA
Team Lead, “Learn the Signs. Act Early.”
Jacquelyn Bertrand, PhD
Behavioral Scientist, FAS Prevention

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities, Prevention Research Branch
Take-Home Points

- Developmental disabilities are common
- Early identification is important
- All providers play an important role in developmental monitoring and early identification
- CDC offers resources, tools, and Ambassadors to help
Developmental Disabilities are Common

- 1 in 6 children in the United States has a developmental disability\(^1\)

- 1 in 88 has an autism spectrum disorder\(^2\)


FASDs are more common than realized

- Most studies include only children with FAS, but conservative estimates are that about 1 in 167 children have an FASD

- Estimates for older children are probably higher

- 12% of women continue to drinking during pregnancy

FASDs:
- FAS
- pFAS
- ARBD
- ARND
- FAE

Learn the Signs. Act Early.   www.cdc.gov/actearly
FASDs are even more common in some vulnerable populations (FAS only – tip of the iceberg)

- U.S. Foster care 1 in 66 children
- Russian orphanages 1 in 66 children
- Juvenile justice 1 in 100 children
- South Africa 1 in 33 children
- Native Americans 1 in 109 children

Higher rates of developmental disabilities could be expected in children in foster care or protective services
Early Intervention Makes a Difference

- **Early intervention services**
  - improve skills and outcomes
  - increase school readiness
  - enable families to develop strategies and obtain resources needed for successful family functioning
  - encourages documentation of important early events and exposures


Too Many are Identified Late

- Most children identified with ASD had a developmental concern documented in their evaluation records before the age of 2 years.

- However, diagnosis often not until after age 4
  - 82% of children with ASD did not have a diagnosis by age 3 years
  - 21% of children with ASD did not have a diagnosis by age 8 years

- Many children with FASDs are not identified until school age – if at all.

Ways to Identify Potential Developmental Disabilities

- Developmental monitoring: use checklist to track child’s developmental milestones

- Developmental screening: use standardized questionnaire at 9, 12, and 24 or 30 months
  - Autism-specific screening at 18 and 24 or 30 months

- Physician refers to specialist

- Provider or parents call early intervention program
To improve early identification of autism and other developmental disabilities so children and their families can get the services and support they need
"Learn the Signs" Program Components

- Health education campaign
- Act Early Initiative
- Research and evaluation
"Learn the Signs" Program Component 1: Health Education Campaign

- Aims to change perceptions about the importance of identifying developmental concerns early
- Gives professionals and parents tools to help track development
- Promotes awareness of the importance of early identification
Campaign Impact

- **Pediatricians aware of the campaign are**
  - More likely to have resources to educate parents about monitoring their child’s development
  - More likely to discuss cognitive and behavioral development with parents
  - More likely to be aware of resources for referral and treatment
  - Less likely to advocate a wait-and-see approach

- **Campaign helped to change how we view child development**
  - Height, weight, first words and steps no longer sufficient
  - How a child plays, learns, speaks, and acts equally important

Daniel et al. Public Health 123 (2009) e11-e16
Strategic Approach

- To work with federal, state and local partners that serve young children

- Some are beginning to integrate “Learn the Signs"
  - WIC clinics
  - Head Start/Early Head Start resource centers
  - ACF Child Care Block Grant recipients
  - Home visiting programs
  - Help Me Grow programs
CDC Offers Free Materials

- Milestone checklists in booklets, brochures, 1-pagers, plus other resources
- Providers and parents can use as monitoring tools
- Useful for any program that serves young children and has interest or mandate in child development – including Children’s Bureau programs
- Encourage parent-provider dialogue
Customizable Materials for Your Programs

All materials are
- Research-based
- Written in plain language
- Reproducible (no copyright)
- Available in English and Spanish
- Available to download or print
- Popular!

www.CDC.gov/ActEarly
ActEarly@cdc.gov
Print Materials

“The Milestones Collection”

- Milestone Checklists
- Milestone Brochure
- Milestone Moments Booklet
- Growth Chart
- “Parent Kit”
Milestone Checklists

Your Child at 2 Years

<table>
<thead>
<tr>
<th>Child’s Name</th>
<th>Child’s Age</th>
<th>Today’s Date</th>
</tr>
</thead>
</table>

How your child plays, learns, speaks, and acts offers important clues about your child’s development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by his or her 2nd birthday. Take this with you and talk with your child’s doctor at every visit about the milestones your child has reached and what to expect next.

What most children do at this age:

- **Social/Emotional**
  - Copies others, especially adults and older children
  - Gets excited when with other children
  - Shows more and more independence
  - Shows defiant behavior (doing what he has been told not to)
  - Plays mainly beside other children, but is beginning to include other children, such as in chase games

- **Language/Communication**
  - Points to things or pictures when they are named
  - Knows names of familiar people and body parts
  - Says sentences with 2 to 4 words
  - Follows simple instructions
  - Repeats words overheard in conversation
  - Points to things in a book

- **Cognitive (learning, thinking, problem-solving)**
  - Finds things even when hidden under two or three covers
  - Begins to sort shapes and colors
  - Completes sentences and rhymes in familiar books
  - Plays simple make-believe games
  - Builds towers of 4 or more blocks
  - Might use one hand more than the other
  - Follows two-step instructions such as “Pick up your toys and put them in the suitcase.”
  - Names items in a picture book such as a cat, bird, or dog

- **Movement/Physical Development**
  - Stands on tiptoe
  - Kicks a ball

**Act early by talking to your child’s doctor if your child:**

- Doesn’t use 2-word phrases (for example, “drink milk”)
- Doesn’t know what to do with common things, like a brush, phone, fork, spoon
- Doesn’t copy actions and words
- Doesn’t follow simple instructions
- Doesn’t walk steadily
- Loses skills she once had

Tell your child’s doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state’s public early intervention program. For more information, go to www.cdc.gov/ncbddd/actearly or call 1-800-CDC-INFO.

This American Academy of Pediatrics recommends that children be screened for general development and autism at the 24-month visit. Ask your child’s doctor about your child’s developmental screening.

Learn the Signs. Act Early.

www.cdc.gov/actearly | 1-800-CDC-INFO
Milestone Checklists

- Useful to raise awareness about developmental milestones for *all* children
  - *NOT* a formal, validated screening tool

- Available online for ages 2 mo – 5 yr

- Helpful for communicating with healthcare provider about a child’s development
Milestones Brochure

Track Your Child's Developmental Milestones

Your child's early development is a journey. Use this map of milestones to know what to look for along the way.

For parents of children from birth to 4 years.

Learn the Signs. Act Early.

- Lists a few milestones for ages 6 months to 4 years
- English and Spanish versions
- Downloadable from the website

Learn the Signs. Act Early. www.cdc.gov/actearly
Milestone Moments Booklet

Healthy Development For Your Child

Healthy Development

What children do at this age – and how you can help their development.

Social/Emotional
- Copies adults and playmates
- Shows affection for playmates without prompting
- Takes turns in games
- Plays well with two or three children in a group
- Cares about others’ feelings
- Understands the idea of “mine” and “his” or “hers”
- Shows affection openly
- Shows a wide range of emotions
- Separates easily from mom and dad
- Gets upset with major changes in routine

How you can help your child’s social and emotional development
- Go to play groups with your child or other places where there are other children, to encourage getting along with others.
- Name your child’s emotions. For example, say, “I can tell you feel mad because you throw the puzzle piece.” Encourage your child to identify feelings in books.
- Work with your child to solve the problem when he is upset.
- Set rules and limits for your child, and stick to them. If your child breaks a rule, give him a time out for 30 seconds in a chair or in his room. Praise your child for following the rules.
- When your child sees another child who is upset, encourage her to offer comfort by giving a hug or a toy.
- During play dates, set a time for trading toys with the other child to encourage sharing and taking turns.

✓ Printable version available on website
✓ Milestones from 2 months - 5 years
✓ Parenting Tips
✓ Developmental Health Watch information
✓ Use on an ongoing basis

Learn the Signs. Act Early. www.cdc.gov/actearly
## Inside Milestone Moments

### Your Baby at 6 Months

**Cognitive (learning, thinking, problem-solving)**
- Looks around at things nearby
- Shows curiosity about things and tries to get things that are out of reach
- Brings things to mouth
- Begins to pass things from one hand to the other

**Movement/Physical Development**
- Rolls over in both directions (front to back, back to front)
- When standing, supports weight on legs and might bounce
- Begins to sit without support
- Rocks back and forth, sometimes crawling backward before moving forward

### How you can help your child learn and grow

- Point out new things to your baby and name them.
- Show your baby bright pictures in a magazine and name them.
- Hold your baby up while she sits or support her with pillows. Let her look around and give her toys to look at while she balances.
- Put your baby on his tummy or back and put toys just out of reach. Encourage him to roll over to reach the toys.

### Parenting tips on development

### Milestone checklists

**Act early by talking to your child’s doctor if your baby:**
- Doesn't try to get things that are in reach
- Doesn't respond to sounds around him
- Has difficulty getting things to mouth
- Shows no affection for caregivers
- Seems very floppy, like a rag doll
- Doesn't roll over in either direction
- Doesn't make vowel sounds (“ah”, “eh”, “oh”)
- Doesn't laugh or make squealing sounds
- Seems very stiff, with tight muscles

**Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to [www.cdc.gov/concerned](http://www.cdc.gov/concerned) or call 1-800-CDC-INFO.**

### Warning signs and Referral information

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Learn the Signs. Act Early. www.cdc.gov/actearly
Growths Chart includes height and milestones with a spot for a photo in the middle. Pairing height and milestones reminds parents there is more than one type of growth.
Parent Kit

Growth Chart

Milestone Moments Booklet

Materials specially packaged for parents - includes one growth chart and one Milestone Moments booklet (English or Spanish).
Other Materials

“Amazing Me—It’s Busy Being 3!”

- Children’s book
- Milestones highlighted throughout story
- Parent section includes 3 year-old milestones, tips, when to act early
- Limited availability

Fotonovela coming soon!
Other Materials, cont.

- **Condition-Specific Fact Sheets**
  - Lay introduction to disability
  - ASD, Asperger’s Syndrome, ADHD, FASD, CP, Intellectual Disability, Vision Loss, Hearing Loss, Duchene’s Muscular Dystrophy

- **Developmental Screening Fact Sheet**

- **National Resource List**
Outreach Materials

- **Flyers**
  - Half sheet
  - General/Parent, Early Educator, Health Professional
- **Exhibit Table Topper**
- **Public Service Announcements**
  - TV & Radio
- “Baby Steps” video
- Web banner ads
- Web buttons
- Widget

Learn the Signs. Act Early. www.cdc.gov/actearly
How to Get LTSAE Materials

- Download and print
- Order free copies (limited)
- Customize

www.cdc.gov/actearly
www.cdc.gov/pronto
ActEarly@cdc.gov
1-800-CDC-INFO
Co-Brand and Customize

- FTP site
- We provide print-ready files (InDesign)
- You plug in your information
- You take files to local printer
- Email ActEarly@cdc.gov
Milestone Moments

Learn the Signs. Act Early.

www.ActEarly.wisc.edu

You can follow your child’s development by watching how he or she plays, learns, speaks, and acts.

Look inside for milestones to watch for in your child and how you can help your child learn and grow.

Learn the Signs. Act Early.  www.cdc.gov/actearly
How to Get Information and Materials about FASDs

www.cdc.gov/fasd
1-800-CDC-INFO
EDang@cdc.gov

Learn the Signs. Act Early. www.cdc.gov/actearly
FASD Resources for parents and case workers
Including foster/adoptive parents

WWW.NOFAS.ORG

Information clearinghouse
Birth Mother’s Support Network
Referrals to local diagnostic clinics
Referrals to local services

Support groups
Advocacy
Research support
Media monitoring

1200 Eton Court, NW, Washington, DC 20007
(202) 785-4585

Learn the Signs. Act Early. www.cdc.gov/actearly
Autism Case Training

- Available online
- Curriculum for classroom (residency) training
- Continuing education online modules
  - CME, CNE, CEU
Autism Case Training (ACT) Curriculum
A Developmental-Behavioral Pediatrics Curriculum

Screening
- Early Warning Signs of Autism
- Screening for Autism

Diagnosis
- Communicating Concerns: Screening and Diagnosis Results
- Making an Autism Diagnosis

Caring for Children with ASD
- Early Intervention and Education
- Treatment for ASDs
- Autism-Specific Anticipatory Guidance

www.cdc.gov/AutismCaseTraining

Learn the Signs. Act Early.  www.cdc.gov/actearly
"Learn the Signs" Program Component 2: Act Early Initiative

- In collaboration with HRSA, AMCHP, AUCD
- Supports state-level priority efforts such as awareness, screening, provider training
- Act Early regional summits 2008 - 2010
- Act Early State Systems Grants (10)
- Act Early Ambassadors (25)
Act Early Initiative Results

- State team leader feedback from interviews, survey
  - Strengthened existing partnerships
  - Improved early identification
  - Established new partnerships

- Post-Summit Activities
  - Education and training
  - Public awareness
  - Policy change

- Most teams continue to meet
Act Early Ambassadors

- Community champions to increase awareness activities and improve early identification practices
- Serve as state or territory point-of-contact for the national LTSAE program
- Support the work of Act Early Teams
- Use and promote Autism Case Training
Find Ambassador Contacts

Learn the Signs. Act Early.

About The Program

CDC’s “Learn the Signs. Act Early.” program aims to raise awareness about autism and other developmental disabilities so families can seek support they need.

The program is made up of three components:

1. Health education campaign
2. Act Early Initiative
3. Research and evaluation

"Learn the Signs. Act Early." Paints the Country Purple. Click on the map for the full story.

Learn the Signs Home
- Milestones
- If You’re Concerned
- Facts
- Free Materials
- Multimedia & Tools
- Info For Families
- Info For Healthcare Providers
- Info For Early Childhood Educators
- Info For Partners
- Get Involved

About the Program
- Health education campaign
- Act Early Initiative
- Research and evaluation

Information For...
- Media
- Policy Makers
Act Early Initiative Drives Campaign to State and Local Level

- Delaware provides customized materials to all pregnant women through home visiting programs and to new mothers.

- Connecticut provides their customized materials to all child care centers in the state.

- Wisconsin distributes materials statewide through Head Start, home visiting, and other programs.

- Alaska mails materials to all new parents.
"Learn the Signs" Program Component 3: Research and Evaluation

- Advance understanding of
  - Information needs of key campaign audiences
  - How to reach special populations
  - How to improve state systems

- Evaluation of campaign strategies
  - IAA with HRSA – supplemental CAAI funding
  - 4 projects (AK, MO, UT, WA)
  - Focused on feasibility, strategy effectiveness
Take-Home Points

- Developmental disabilities are common
- Early identification is important for all developmental disabilities and especially ASD & FASDs
- Your providers play an important role in developmental monitoring and early identification
- CDC offers resources, tools, and Ambassadors to help
Questions/Discussion

RWolf@cdc.gov
JBertrand@cdc.gov

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov Web: www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.