Acknowledgements

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Background

- Prevalence estimates indicate that approximately 1 in 6 children in the U.S. has a developmental disability.[1]

- However, only 2.8% of the population of infants and toddlers receive early intervention services.[2]

- Recent efforts have emphasized the key role pediatricians and other health care providers play in helping to identify developmental delays by monitoring milestones and conducting routine developmental screenings during well-child checkups.[3-6]

- Parents also have been shown to be as accurate as standardized screening tools in identifying potential developmental delays.[7]

CDC's Learn the Signs. Act Early. Campaign

- Goal is to assist parents and health care providers in the early identification of development delay.
  - Provides resources on early childhood development, including developmental milestones.
  - Encourages parents to act early if they have concerns about their child's development by:
    - monitoring progress on developmental milestones;
    - talking to their health care provider;
    - seeking developmental screening, or contacting their local early intervention program for a multidisciplinary evaluation.

Study Objectives

- To reassess the LTSAE approach of promoting parents' awareness of child development and developmental milestones.

- The research focused on three main interests of the LTSAE campaign:

  - Parental awareness, knowledge, and information needs;

  - Parental attitudes, values, and beliefs; and

  - Parental action.

Methods and Analysis

- In-person focus groups (n=11)
  - 6 in Spanish language and 5 in English
- Parents of children with identified delay or disability (n =74)
- Six U.S. cities
  - Colorado (Colorado Springs and Denver),
  - New York (Bronx and Washington Heights), and
  - North Carolina (Research Triangle Park and Greensboro).
- Developed and used a discussion guide
  - Three time points: First concerns, Seeking help, Starting services
- Analyzed transcripts of audio-recorded interviews and conducted thematic analysis to identify causal and logical statements

Participants

- Gender
  - 68 females and 3 males
- Age
  - 29 to 35 years old
- Education
  - Just over half (55%) had a high school education or less
- Income
  - The majority of participants (77%) had annual incomes below $30,000

Discussion Guide Topics

First Concerns	Seeking Help	Starting Services
• Who was the first to become concerned about the child's development?	• What did they do after they were first worried about their child's development?	• What were parents' experiences starting services for their child's delay?
• What was the concern?	• To whom did they talk, how long did they wait, and what did the doctor or other professionals say about their concerns?	
• How old was their child?		

Key Findings: First Concerns

- Typically, **a parent was first person to express concern** about child's development

    - Most concerns stemmed from delayed speech/a lack of words

    - Occurred between 1-2 years of age

- Many parents **compared their child's development with other children** to get a sense that something might be wrong.

    - More challenging for first time parents due to lack of knowledge about developmental milestones

- Parents referred to **multiple sources of information** about child development (e.g., books, the Internet, friends and family).

- Parent's emotions ranged from **denial to depression.**

Parental Quotes: First Concerns

- "My child hurt himself; he was frustrated that he couldn't speak." (NY – Spanish)

- "So it was really hard to say, 'Are my concerns valid or am I just expecting him to follow suit with his brother?'" (CO – English

- "One of our mistakes was that when we spoke with other people about this, they said, 'Do not worry. Usually boys are lazy to talk.' Sometimes, I, as a first time mother, thought that they were right." (NC – Spanish)

- "I feel there was a ball dropped somewhere and I feel responsible because I wasn't more, you know, aggressive with it." (CO – English)

Key Findings: Seeking Help

- Most parents **talked with their doctor** about their concerns.

  - A few parents talked with a specialist first or their child's teacher.

- There appear to be **two types of doctors**.

  - *Facilitators* and *Monitors*

Facilitators

- **Often asked about** the child's development and progress,

- Had the parents **complete questionnaires** at each visit, and

- When a concern was noted, they **acted quickly to refer** the child and family to a specialist or early intervention.

Parental Quotes: *Facilitators*

- "My doctor is a very good pediatrician. Love him to death. He told me, 'You know what, you know your child better than anybody out here." (NY – English)

- "Every time I took my children to the doctor's office, I would fill out a questionnaire and sign it." (NC – Spanish)

- "My doctor was really proactive and I thought she was jumping the gun a little bit. But I'm glad we went with her recommendation." (CO – English)

Monitors

- **Did not discuss** the child's development regularly with parents,

- Were more likely to say **"wait and see"** when the parent expressed a concern, and

- **Did not frequently provide information** on early intervention or where to seek additional support.

Parental Quotes: *Monitors*

- "The doctor kept saying, 'Oh, he's fine. He'll talk when he wants to.'" (CO – English)

- "Give it time, he'll start talking. He'll grow out of it." (NY – English)

- "Yeah, just kind of like we were having coffee and discussing it. I didn't get any guidance or anything and I knew he should have been at least having, like, a couple of 'Ma' or first words, and especially around 12 and 15 months. It was just kind of frustrating not getting any guidance or anything as to what to do." (CO- English)

Parent's Reactions to *Monitors*

- Parents who were **told to wait and see** had a variety of reactions.
  - Some **changed doctors**.
  - Others were **persistent** and asked their doctor for help or a referral.
  - Only a few parents mentioned **waiting before acting** on their concerns.

Key Findings: Starting Services

- Parent's mentioned **delays in receiving a diagnosis** and/or receiving services

  - Delays ranged from **1 month to 7 months**.

- **Few parents knew about early intervention** or school services prior to their child being identified.

  - Personal experience (e.g., friend or older child receiving services) and media outlets were cited as sources of knowledge of services.

Summary

- Parents turn to multiple sources for information about developmental milestones, including comparing their child to other children the same age.

- Parents are most often concerned about their child's language development.

- Concerns often start between 1 and 2 years of age.

- The possibility of a development delay was met with a variety of emotions.

Summary (continued)

- Parents whose doctors were *facilitators* often were more aware of typical child development and what milestones to look for next.

- Parents whose doctors were *monitors* were often told to "wait and see" when a concern was expressed.

- Overall, parents lacked knowledge about who to contact or where to go when they were worried their child might have a developmental delay.

Implications for the LTSAE Campaign

- **Continued education** about developmental milestones and signs of developmental delay.

  - Despite the availability of information on child development, there appears to be a continued need for information on developmental milestones, especially for low-income parents.

- Emphasis on *how* **parents can act early** when concerned about their child's development.

  - Parents need information and support on how to talk to their child's health care provider about their concerns, especially if there child's provider says "wait and see," and where else they could go for help.

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Early Identification and Connection to Services among Low-Income, Low Literacy Urban Parents

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RTOI Topic:

Narrowing Gaps in Early Identification Among Underserved Population Groups

Our emphasis:

- **Parents with low literacy**

- **Children birth through 4 years**

- **Urban setting - Atlanta**

- **Low income families**

The problem:

Children with DD/ASD who are from minority groups, live in poverty, and have parents with little education are often diagnosed at later ages than their counterparts

- Children of lower SES were less likely to be identified with ASDs prior to entering school (Yeargin-Allsopp et al., 2003)

- Near-poor children received ASD diagnoses later than their higher income counterparts (Mandell et al., 2005)

Parents are often the first to note delays in child development

- **When children experience delays, some parents develop concerns; other parents do not**

- **Some parents act based on their concerns; others do not**

- **The actions of some parents result in formal screening and/or services, others do not**

Why?

Ajzen's (1991) Theory of Planned Behavior
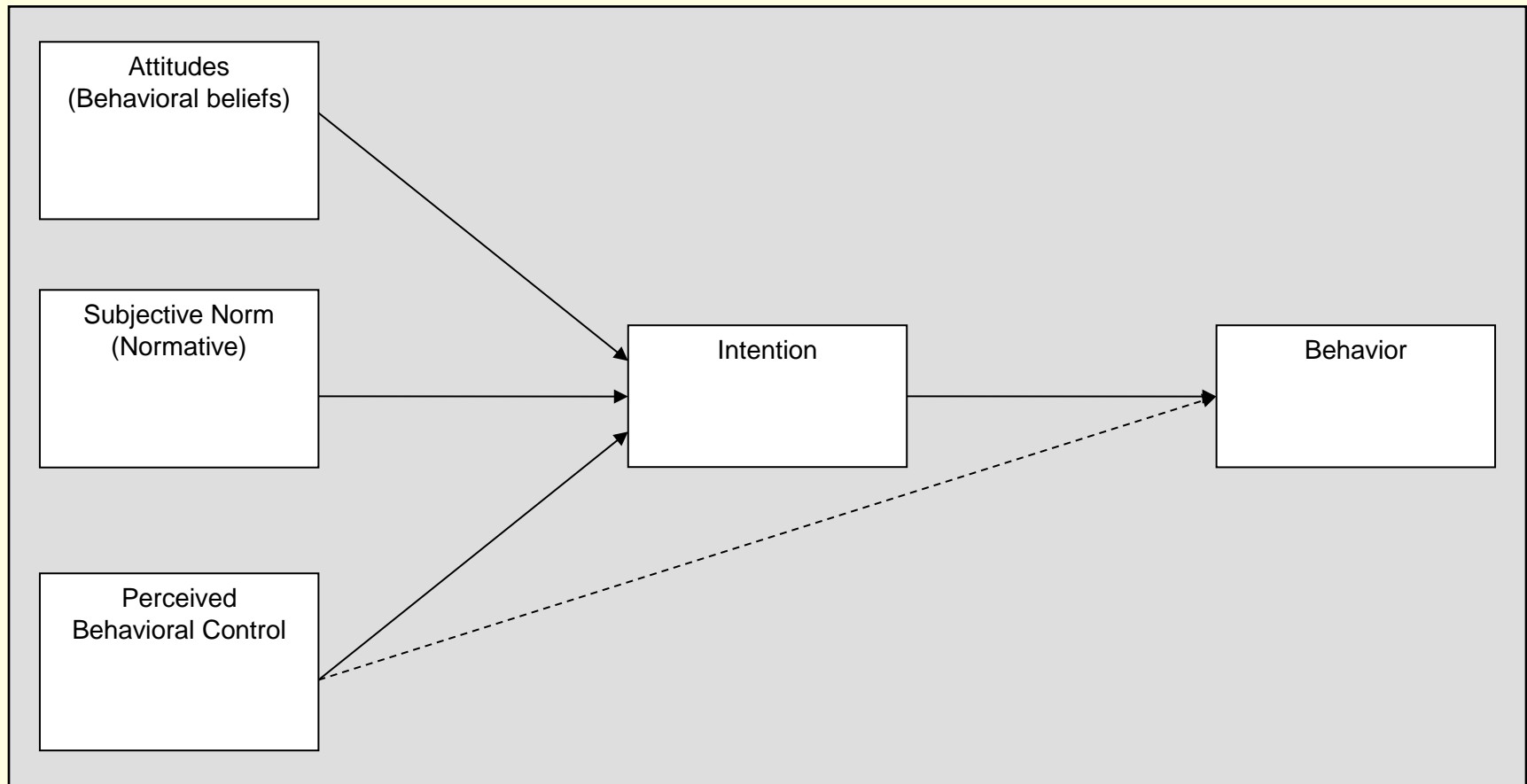
Theory of Planned Behavior

- *Knowledge and attitudes* (e.g., "How do you get information? Have you had concerns about your child?")

- *Subjective norm* (e.g., "Have you discussed your child's behavior with family members? What would/did people important to you think if you were to seek help? ")

- *Perceived control* (e.g., "If you /when you needed help for your child because of development or behavior, where would/did you go - how easy would it be/was it to get help?")

- Intentions (e.g., "Do you intend to pay close attention to your child's development and behavior?")

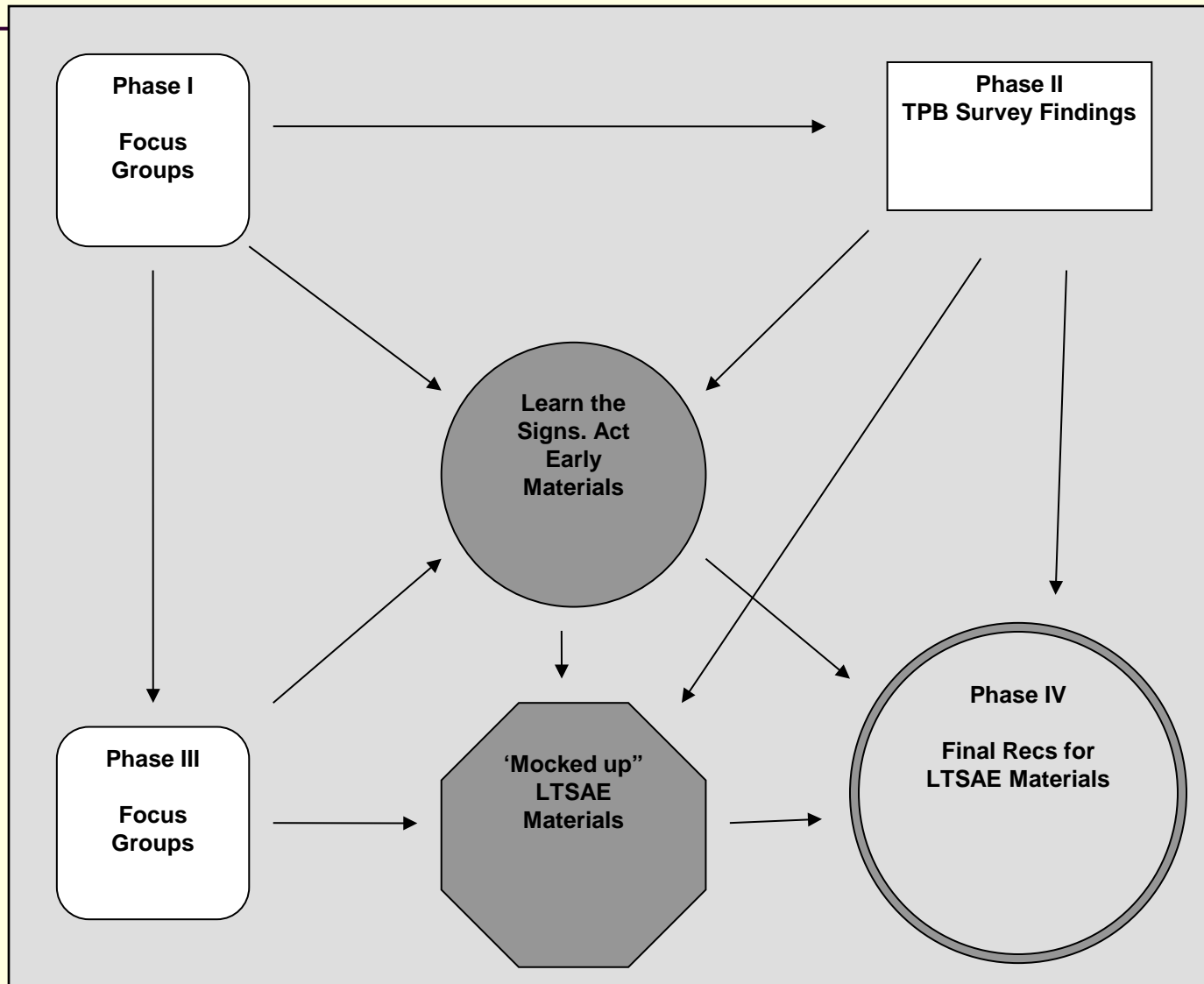- *Behavior* (e.g., "How did you find services? What did you do?")

Research Plan

- **Focus groups**

  - **Parents with low literacy**

  - **Parents of children in early intervention/ECSE**

  - **Gain insight into parents' thinking about development**

  - **Have parents provide feedback on LTSAE materials**

- **Survey**

  - **Tested utility of Theory of Planned Behavior for screening and monitoring**

- **Developed 'mock up' of revised LTSAE materials**

Overall Framework for Research Activities

Phase I

Focus Groups

Phase II
TPB Survey Findings

Learn the Signs. Act Early Materials

Phase III

Focus Groups

'Mocked up" LTSAE Materials

Phase IV

Final Recs for LTSAE Materials

The Importance of Literacy Research

1 in 6 adults have low literacy skills and therefore have difficulties reading and understanding printed materials (PIAAC, 2013).

Literacy and Health Education

- **Lack of literacy skills major obstacle to effective health care communication**

- **Research finds that most health education materials are written at a very high level**

- **Recommended level:**

  - **6th grade for 75% of population**
  - **3rd grade for 90%**

Focus Groups

Participants – parents of young children

- **Parents with low literacy**

- **Parents receiving early intervention/early childhood special education services**

Focus Groups

Six small focus groups held

2 – 3 hours per focus group

17 mothers of young children participated

88% African American

Reading level – 4th to 8th grade

Focus Groups

Sessions divided into 2 segments:

- **Thinking about development**

- **Responding to LTSAE materials**

Focus Groups – First Segment
Thinking About Development

Based on Theory of Planned Behavior

- *Knowledge and attitudes*

- *Subjective norm*

- *Perceived control*

- *Intentions*

- *Behavior*

Where do parents get information about child development?

- **Family/friends**
- **Doctor**
- **Hospital at birth/parenting classes**
- **Teachers/home visiting nurses**
- **Health dept. when child immunized**
- **WIC, DFACS**
- **Computer searches**

Where do parents get information about child development?

- TV shows – "Nanny 911", autism shows
- TV at doctor's office while waiting
- United Way 211 line

Insurance Hotlines

Available to parents 24/7

"You can call in the middle of the night; it doesn't matter, I've called plenty of times like 2 or 3 in the morning; they gonna pick up as soon as you call"

Focus Groups – Second Segment

Evaluation of LTSAE Materials

- **Readability – circle difficult words**

- **Comprehensibility**

- **Persuasiveness**

- **Messages conveyed by visual images**

- **Likelihood of creating behavioral change**

- **Clarity**

LTSAE Materials Evaluated - Parent Flyer

Parent Flyer

Her first tooth!
And she's babbling!

It's time to change
how we view a child's growth.

From birth to 5 years, there are milestones children should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. Fortunately, the earlier a delay is recognized, the more you can do to help them reach their full potential.

To request a FREE kit,
visit www.cdc.gov/actearly.

Learn the Signs. Act Early.

Attractive
Nice color and pattern
Type is a good size
A lot of "white space"
Not too many words on the page

■ **P1:** This one because, like I said, it's less words or not so many words in here. And they can be easier to understand because less words.

Very Cute Baby!

- **P3:** Aw.
- **PG:** Everybody likes that picture.
- **P3:** I wanna pinch those cheeks.

- **P2:** The picture draws your attention-
- **P3:** It makes you want to look at it and read it.

CDC Is a Trusted Source of Information

- **P1:** I like the idea that they got the CDC written on there because that stands out to be informative.
- **JC:** Okay.
- **P1:** To be informative for health reasons.
- **P2:** People trust the CDC.

Parent Flyer

Her first tooth!
And she's babbling!

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Learn the Signs. Act Early.

Terms "**babbling**", "**milestone**" and "**potential**" hard to understand

Want a phone number to call

■ **P3:** **So if you could have a phone number where you can instantly call someone and talk to them right away.**

"Her first tooth! And she's babbling!"

Her first tooth! And she's babbling!

Handout is about:

**Going to the dentist?
Care of teeth?
Teething?**

A Literal Interpretation

- **P2: Here is her first tooth and she's babbling, what does that have to do with-**
- **P3: Developmental delays?**
- **P2: What does her tooth have to do? Your teeth gonna grow in at the regular schedule-**
- **P3: Regardless. That has nothing to do with a delay.**

A Literal Interpretation

- **P3:** Request more information. More information about what?

- **P2:** About her teeth coming in?

- **P2:** I mean, how to handle when the tooth come in.

- **P3:** Right.

- **P3:** You know, then they have autism in here and that kind of, like, mixes everything up and makes it even, like, more confusing.

- **P3:** So what? You want me to request more information about teeth and autism?

Parents Liked the Free Kit

- **P3:** …I might pick it up.
- **J:** So you would look at it probably cause it has a cute little baby-
- **P2:** No, what would get me is all that request a free kit.

To request a FREE kit,
visit www.cdc.gov/actearly.

Learn the Signs. Act Early.

What is in the free kit?

P3: And it says request a free kit. Of what?
P2: Yeah I was gonna say what kit? What's in the kit?

P2: Or if you get a free kit it's a whole bunch of coupons for like Simalac or something trying to…you know what I mean?

"It's time to change how we view a child's growth."

A different way of thinking about physical growth?

Parents were confused by the key campaign phrase, "It's time to change how we view a child's growth".

After reading the phrase, most thought the campaign focused on physical growth. They tended toward a concrete interpretation of the phrase and did not relate to the juxtaposition of physical growth and child development.

Participants suggested changing from "It's time to change how we view a child's growth" to "It's time to change how we view a child's development."

- **D:** What does the title mean to you? *"It's Time to Change How We View a Child's Growth."* What do you think they're trying to get at there?
- **P2:** Make sure your kid's growing right.

- **P2:** Growth.
- **P3:** Right.
- **P2:** It's making you-
- **P1:** Right, growth.
- **P3:** It's confusing.
- **J:** So that's confusing, the growth part again?
- **P2:** Yeah.

- **P1: It's time to change how we view a child's growth.**
- **P3: No, Learn the signs. Act early should be up top.**
- **P3: So you need to take…let's get rid of this and put Learn the signs. Act early. Boom.**

- **P2:** I think so. And I like this logo **"Learn the Signs, Act Early."** I like that.
- **JC:** What do you like about that?
- **P2:** 'Cause it's actually telling you, you know what to do. **Learn the signs and act early**.
- **P1:** I think it would be great if that was up on top.
- **JC:** Okay.

Autism Is a "Scary" Word

- **P3:** Like I said it freaks me out…Cause you want to know but you don't want to know. ..

- **P1:** …maybe there is something there but not scaring you like just because you see this sign-

- **P3:** You're gonna have autism, you're gonna have autism.

- **P1:** Like this here, if you see something wrong with your child it gotta be autism.

- **P3:** That like, that freaks me out a little bit but it also makes me aware. Like you know I need to start watching my child a little bit more closely. But that word autism just like ooo. You know? So maybe just delays.

- **P2:** Cause you're giving it a name. It's like omg if your child's delayed they're gonna have autism.

LTSAE Second Flyer

Original Text:

From birth to 5 years, there are milestones children should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. Fortunately, the earlier a delay is recognized, the more you can do to help them reach their full potential.

Suggested Text:

It's time to change
how we view a child's growth.

From birth to 5 years, there are milestones children should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. Fortunately, the earlier a delay is recognized, the more you can do to help them reach their full potential.

To request a FREE kit,
visit www.cdc.gov/actearly.

Learn the Signs. Act Early.

Children learn to do many things as they grow. Skills like waving "bye bye" or walking are called milestones. Children reach many milestones from birth to 5 years. If they are off track, it could be a sign of a delay. But there is good news. The earlier you catch a delay, the more you can do to help your child. Learn the signs to see if your child is on track.

Suggested Revised Flyer

LTSAE Materials Evaluated - Growth Chart

Growth Chart

It's time to change how we view a child's growth.

4 feet

47"
46"
45"
44"
43"
42"
41"
40"

space for photo

5 years

Speaks very clearly

Wants to please friends and wants to be like friends

Counts 10 or more things

Can tell what's real and what's make-believe

4 years

Tells stories

Understands the ideas of "same" and "different"

Plays "Mom" or "Dad"

Cooperates with other children
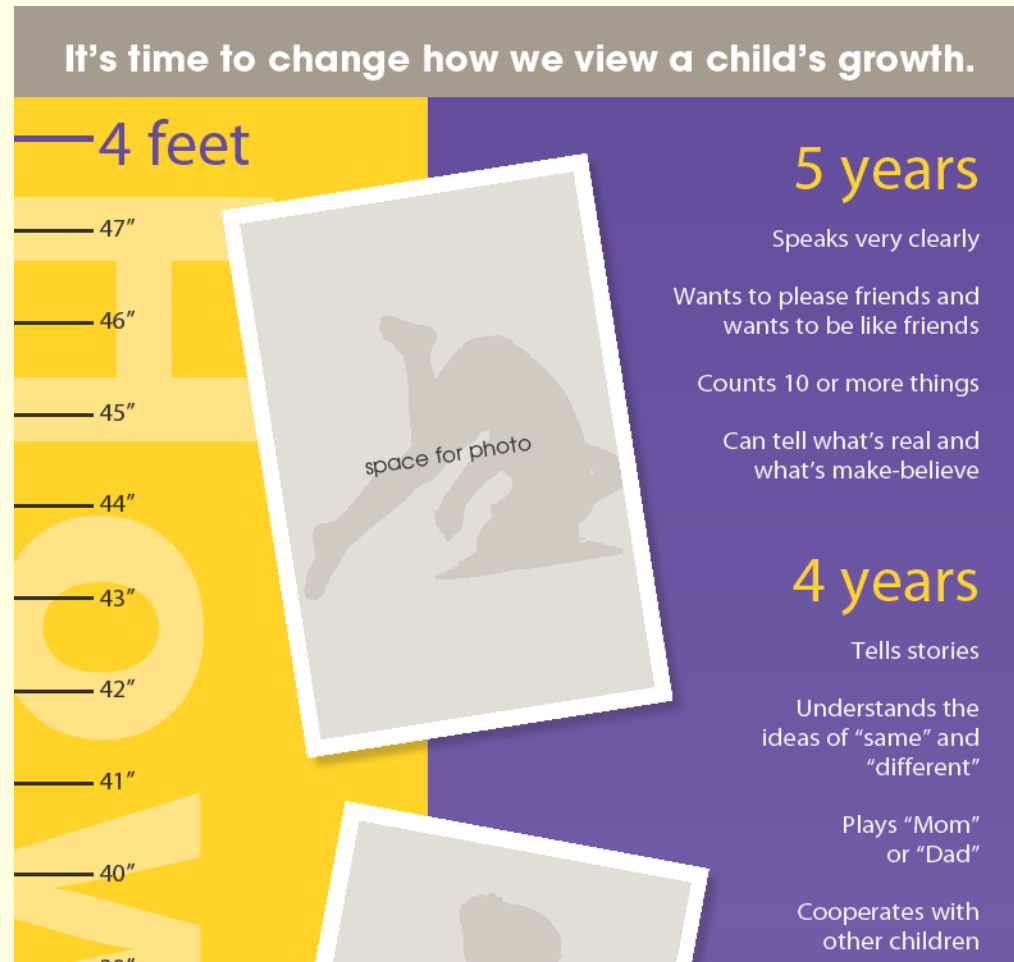
Positives

The item parents were the most likely to take home. Parents wanted to put it on the wall at home.

Negatives

**Yellow print on yellow background
Difficult words
Wanted more examples
Wanted LTSAE message at the top**

Parents Really Liked the Growth Chart

- **D:** Is this something that if you saw in the doctor's office you'd wanna take home?

- **P4:** Yes.

- **P3:** I think they should make one though blue.

- **P2:** I'd probably take like 3 of them.

- **P1:** It just really stands out more than the other 2 things that you passed out. This just stands out a whole lot more.

- **P3:** Actually, this just, this my favorite one.

- **P1:** Yeah, I think so too.

- **P4:** … it's cute.
- **P2:** It give you ideas to do with your own, put your own kid's photo on there.
- **P3:** Yeah, it's something you want to take and read over.
- **P2:** It's cute, it's something you wanna take and you wanna read it.
- **P3:** And at the same time you doing something that you really need to do cause your child can't, might not be growing right. You not even paying attention to it cause, you know, you might peek up on it.

Believed that Chart Was About Physical Growth

It's time to change how we view a child's growth.

4 feet

47"

46"

45"

44"

43"

42"

41"

40"

space for photo

5 years

Speaks very clearly

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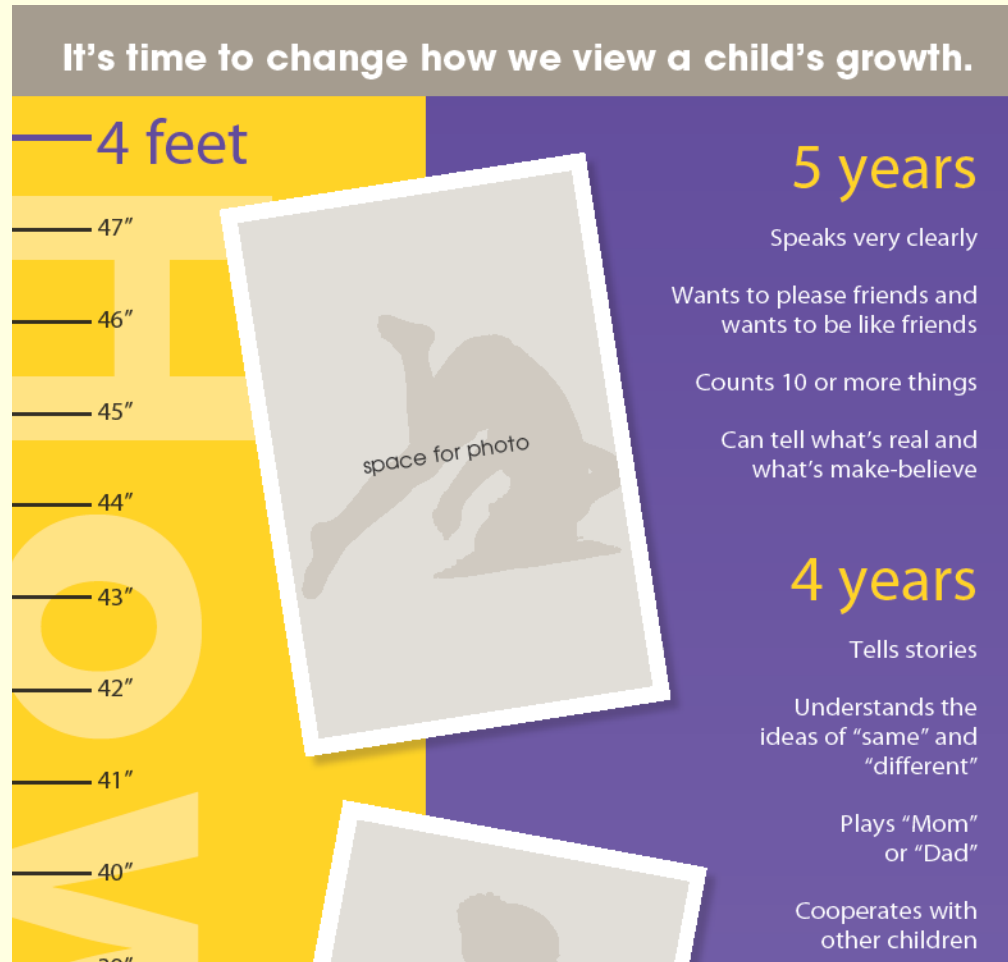
- **P3:** … But maybe this is confusing because it tells you about your child's growth versus your child's development. It makes you look more…it brings more focus to your child's height versus the development.

Height, Developmental Milestones, and Age Linked Together

It's time to change how we view a child's growth.

4 feet

47"
46"
45"
44"
43"
42"
41"
40"

space for photo

5 years

Speaks very clearly

Wants to please friends and wants to be like friends

Counts 10 or more things

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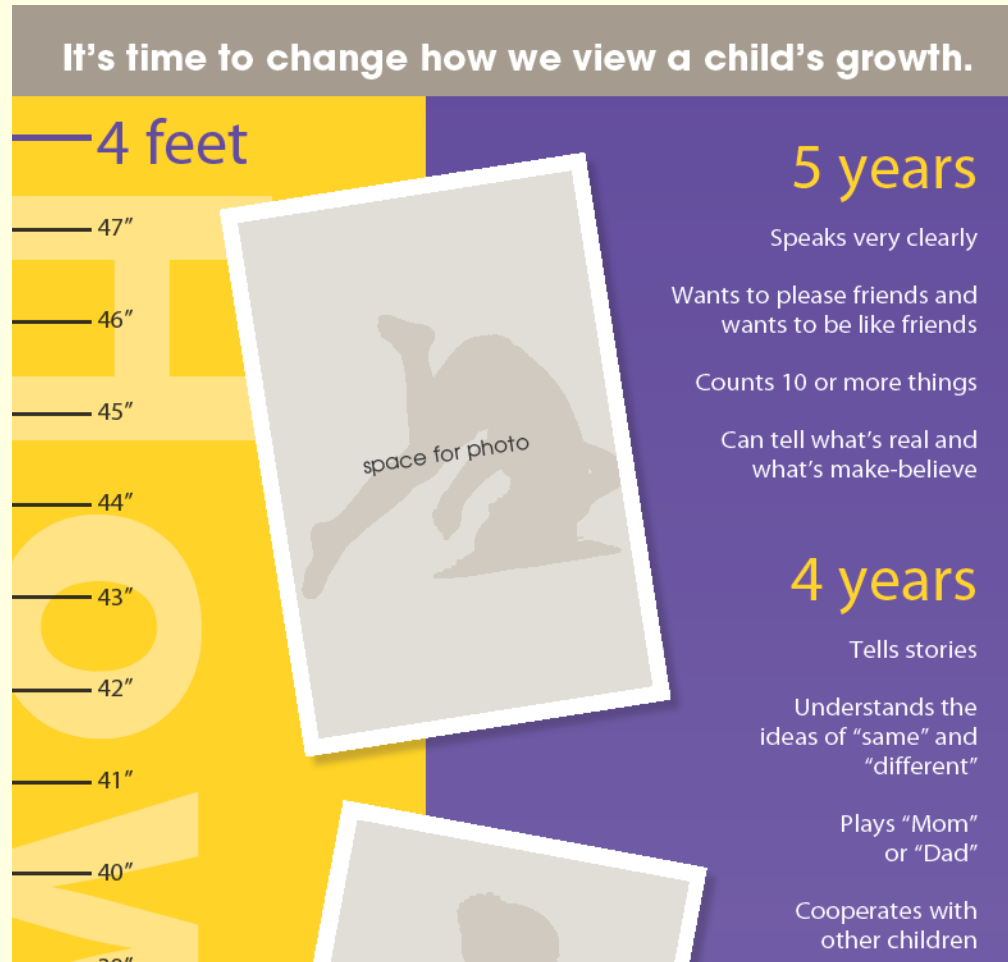
- **P3:** They gonna be 4 feet tall at 5 years old? Is your child…is your child 4 feet tall should they be 5 years old?

- **P2:** It says your child's gonna be that tall then he should be talking like this.

- **P3:** See this is confusing to me. That is what I thought. Does that make sense what I just said?

- **P2:** xx developmental issues-

- **P3:** I'm like, it doesn't say anything about developmental…like he's 4 feet tall he should be 5. So if he's 4 feet tall he's 5. Okay so, okay well you're 4 feet tall now, so know your name. What's your name? What's your address?

- **P2:** I think, I think basically it speak for itself. It means it's time to change how we view our child's growth and showing that like the years and maybe how tall they should be. .

- **D:** Well what do you think would be an example of why somebody would call a 1-800 number off of this chart?

- **P2:** Ask em a word or like if they wanna know more information about their child's height, you know, or they –

Growth Chart
Recommended Text at Top of Chart

It's time to change how we view a child's growth.

4 feet

47"

46"

45"

space for photo

44"

43"

42"

41"

40"

5 years

Speaks very clearly

Wants to please friends and wants to be like friends

Counts 10 or more things

Can tell what's real and what's make-believe

4 years

Tells stories

Understands the ideas of "same" and "different"

Plays "Mom" or "Dad"

Cooperates with other children

Children learn to do many things as they grow. Skills like waving "bye-bye" or walking are called milestones. Children reach many milestones from birth to 5 years. Use this chart to keep track of your child's milestones as you child grows.

LTSAE Materials Evaluated - Informational Card

It's time to change how we view a child's growth.

As they grow, children are always learning new things. Below are just some of the things you should look for as your child grows. Use this as a guide, and if you have any concerns, talk with your child's doctor and call **1-800-CDC-INFO** to get connected with your community's early childhood intervention system.

▶ At 6 months, many children
- respond to own name
- respond to other people's emotions and often seem happy
- copy sounds
- like to play with others, especially parents

▶ At 1 year (12 months), many children
- use simple gestures, like shaking head "no" or waving "bye-bye"
- say "mama" and "dada" and exclamations like "uh-oh!"
- copy gestures
- respond to simple spoken requests

▶ At 1 ½ years (18 months), many children
- play simple pretend, such as feeding a doll
- point to show others something interesting
- show a full range of emotions, such as happy, sad, angry
- say several single words

▶ At 2 years (24 months), many children
- say sentences with 2 to 4 words
- follow simple instructions
- get excited when with other children
- point to things or pictures when they are named

▶ At 3 years (36 months), many children
- show affection for friends without prompting
- carry on a conversation using 2 to 3 sentences
- copy adults and friends
- play make-believe with dolls, animals, and people

▶ At 4 years (48 months), many children
- tell stories
- would rather play with other children than by themselves
- play cooperatively with others

▶ Questions to ask your child's doctor:
- Is my child's development on track for his or her age?
- How can I track my child's development?
- What should I do if I'm worried about my child's progress?
- Where can I get more information?

Adapted from CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5, Fifth Edition, edited by Steven Shelov and Tanya Remer Altmann © 1991, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics.

www.cdc.gov/actearly
1-800-CDC-INFO

Learn the Signs. Act Early.

Informational Card

Parents liked the idea of a developmental milestone checklist

- **D:** So if you were to get something like this, what would you think about your child?

- **P2:** I think it'd really help me…It's exactly what you're looking for. It answers your questions, it has the milestones. It has simple, the things they should be doing.

Informational Card

Parents also liked the "questions to ask your child's doctor" – but wanted the font for the header to be larger and the color to be darker

Questions to ask your child's doctor:
- Is my child's development on track for his or her age?
- How can I track my child's development?
- What should I do if I'm worried about my child's progress?
- Where can I get more information?

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www.cdc.gov/actearly
1-800-CDC-INFO

CDC
CENTERS FOR DISEASE
CONTROL AND PREVENTION

Learn the Signs. Act Early.

220791

- **Parents wanted the card to be larger, with larger font size**
- **Card was more attractive to more advanced readers**
- **Replace header with Learn the Signs Act Early – instead of It's time to change how we view a child's growth**

LTSAE Materials Evaluated - Dev. Screening Fact Sheet

Developmental Screening
FACT SHEET

What is child development?

A child's growth is more than just physical. Children grow, develop, and learn throughout their lives, starting at birth. A child's development can be followed by how they play, learn, speak, and behave.

What is a developmental delay? Will my child just grow out of it?

Skills such as taking a first step, smiling for the first time, and waving "bye bye" are called developmental milestones. Children reach milestones in playing, learning, speaking, behaving, and moving (crawling, walking, etc.). A developmental delay is when your child does not reach these milestones at the same time as other children the same age. If your child is not developing properly, there are things you can do that may help. Most of the time, a developmental problem is not something your child will "grow out of" on his or her own. But with help, your child could reach his or her full potential!

What is developmental screening?

Doctors and nurses use developmental screening to tell if children are learning basic skills when they should, or if they might have problems. Your child's doctor may ask you questions or talk and play with your child during an exam to see how he or she learns, speaks, behaves, and moves. Since there is no lab or blood test to tell if your child may have a delay, the developmental screening will help tell if your child needs to see a specialist.

Why is developmental screening important?

When a developmental delay is not recognized early, children must wait to get the help they need. This can make it hard for them to learn when they start school. In the United States, 17 percent of children have a developmental or behavioral disability such as autism, mental retardation, or Attention-Deficit/Hyperactivity Disorder (ADHD). In addition, many children have delays in language or other areas. But, less than half of children with problems are identified before starting school. During this time, the child could have received help for these problems and may even have entered school more ready to learn.

I have concerns that my child could have a developmental delay. Whom can I contact in my state to get a developmental assessment for my child?

Talk to your child's doctor or nurse if you have concerns about how your child is developing. If you or your doctor think there could be a problem, you can take your child to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older) for help. To find out who to speak to in your area, you can contact the National Dissemination Center for Children with Disabilities by logging on to **www.nichcy.org/states.htm**. In addition, the Centers for Disease Control and Prevention (CDC) has links to information for families at (**www.cdc.gov/actearly**). If there is a problem, it is very important to get your child help as soon as possible.

How can I help my child's development?

Proper nutrition, exercise, and rest are very important for children's health and development. Providing a safe and loving home and spending time with your child – playing, singing, reading, and even just talking – can also make a big difference in his or her development.

For other ideas of activities to do with your child, and for child safety information, go to **www.cdc.gov/ncbddd/child/** and look in the "developmental milestones" section.

www.cdc.gov/actearly

Learn the Signs. Act Early.

LTSAE Materials Evaluated - ASD Fact Sheet

Autism Spectrum Disorders
FACT SHEET

What are autism spectrum disorders?

Autism spectrum disorders (ASDs) are a group of developmental disabilities caused by a problem with the brain. Scientists do not know yet exactly what causes this problem. ASDs can impact a person's functioning at different levels, from very mildly to severely. There is usually nothing about how a person with an ASD looks that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most people. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. Autistic disorder is the most commonly known type of ASD, but there are others, including "pervasive developmental disorder-not otherwise specified" (PDD-NOS) and Asperger Syndrome.

What are some of the signs of ASDs?

People with ASDs may have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASDs also have different ways of learning, paying attention, or reacting to things. ASDs begin during early childhood and last throughout a person's life.

A child or adult with an ASD might:
- not play "pretend" games (pretend to "feed" a doll)
- not point at objects to show interest (point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds

www.cdc.gov/actearly

- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- repeat actions over and over again (hand flapping, finger movements, rocking, etc.)
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for instance, stop saying words they were using)

* Note: Contact your child's doctor or nurse if your child experiences a dramatic loss of skills at any age.

What can I do if I think my child has an ASD?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, ask for a referral to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out who to speak to in your area, you can contact the National Information Center for Children and Youth with Disabilities (NICHCY) by logging onto **www.nichcy.org/states.htm**. In addition, the Centers for Disease Control and Prevention (CDC) has links to additional information for families at **www.cdc.gov/autism**.

Right now, the main research-based treatment for ASDs is intensive structured teaching of skills, often called behavioral intervention. It is **very** important to begin this intervention as early as possible in order to help your child reach his or her full potential. Acting early can make a real difference!

Learn the Signs. Act Early.

LTSAE Fact Sheets

- **Parents with greater reading ability liked the fact sheets**

- **Parents with lower reading ability were not interested in the materials**

Recommendations

- **Use a clear header at the top of all materials**

- **Keep themes and messages concrete – anticipate literal interpretation of information- avoid abstractions**

- **Use a large font - put important points in bold font**

- **Allow ample white space**

- **Use few words on each document**

Recommendations

- **Use pictures when possible**

- **Replace or define difficult words like "milestones"**

- **Include a phone number where parents can ask questions and engage in conversation**

- **Use numbers, not letters, for phone numbers**

- **Check that visuals match the text**

These guidelines make materials more accessible for
EVERYONE!

Thank You!

Original text:

From birth to 5 years, there are milestones children should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. Fortunately, the earlier a delay is recognized, the more you can do to help them reach their full potential.

It's time to change how we view a child's growth.

As they grow, children are always learning new things. Below are just some of the things you should look for as your child grows. Use this as a guide, and if you have any concerns, talk with your child's doctor and call 1-800-CDC-INFO to get connected with your community's early childhood intervention system.

► At 6 months, many children
- respond to own name
- respond to other people's emotions and often seem happy
- copy sounds
- like to play with others, especially parents

► At 1 year (12 months), many children
- use simple gestures, like shaking head "no" or waving "bye-bye"
- say "mama" and "dada" and exclamations like "uh-oh!"
- copy gestures
- respond to simple spoken requests

► At 1 ½ years (18 months), many children
- play simple pretend, such as feeding a doll
- point to show others something interesting
- show a full range of emotions, such as happy, sad, angry
- say several single words

► At 2 years (24 months), many children
- say sentences with 2 to 4 words
- follow simple instructions
- get excited when with other children
- point to things or pictures when they are named

► At 3 years (36 months), many children
- show affection for friends without prompting
- carry on a conversation using 2 to 3 sentences
- copy adults and friends
- play make-believe with dolls, animals, and people

► At 4 years (48 months), many children
- tell stories
- would rather play with other children than by themselves
- play cooperatively with others

► Questions to ask your child's doctor:
- Is my child's development on track for his or her age?
- How can I track my child's development?
- What should I do if I'm worried about my child's progress?
- Where can I get more information?

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From birth to 5 years, there are milestones children should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. Fortunately, the earlier a delay is recognized, the more you can do to help them reach their full potential.
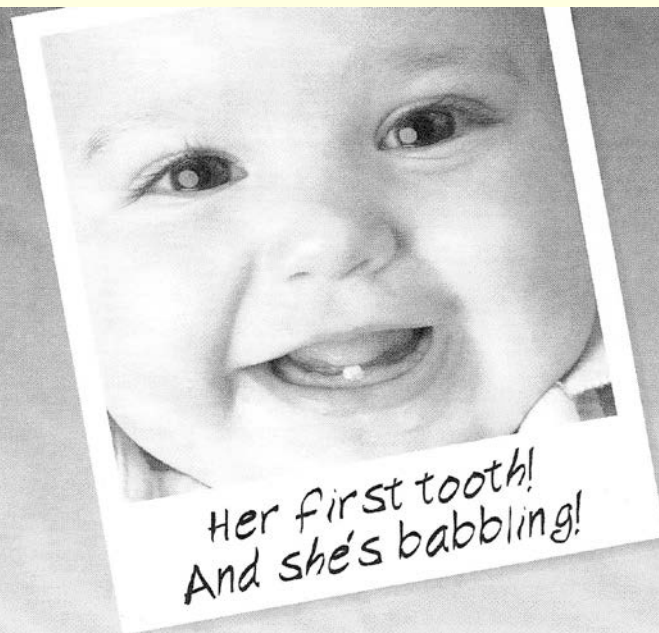

Questions to ask your child's doctor:

- Is my child's development on track for his or her age?
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www.cdc.gov/actearly
1-800-CDC-INFO

Learn the Signs. Act Early.

Her first tooth!
And she's babbling!

It's time to change
how we view a child's growth.

From birth to 5 years, there are milestones children should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. Fortunately, the earlier a delay is recognized, the more you can do to help them reach their full potential.

For **FREE** information about milestones and **FREE** tools to help track a child's development, visit **www.cdc.gov/ActEarly** or call **1-800-CDC-INFO**.

Learn the Signs. Act Early.

Authors and Acknowledgement

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Georgia State University | CENTER FOR LEADERSHIP IN DISABILITY

Background

- Disparities persist for children from underserved backgrounds in follow-through on screening, age of diagnosis, and types and intensity of services received

- CDC's **Learn the signs. Act early.** (*LTS/AE*) campaign is committed to increasing screening and early identification of developmental delays for **all** children

Project Goals

- Immediate goal: Assess the impact of ***LTS/AE Milestone Moments*** booklet delivered by home visitors (HVs) to underserved families

- Long-term goal: Demonstrate an effective approach to increasing developmental awareness of underserved families and follow-up of their children with developmental delays

RCT and Interview Follow-up

- Phase 1: Conduct a randomized controlled trial (RCT) on the context in which *Milestone Moments* is provided to families

- Phase 2: Conduct interviews with families who received the *Milestone Moments* booklet

Milestone Moments

- ## Organization of the *Milestone Moments* booklet
  - Ages – 2 months to 5 years
  - Developmental Domains
    - Social/Emotional
    - Language/Communication
    - Cognitive
    - Movement/Physical Development
  - Act Early signs
  - "How you can help your child's development"
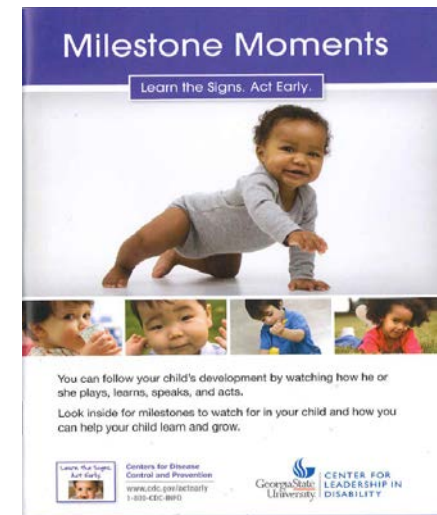
Getting Started Locally

- Sheltering Arms (SA) Early Education & Family Centers
  - 1) high quality, affordable child care and early education, 2) comprehensive family supports, 3) professional development, and 4) community building partnerships
  - 3,600 children and their families - 16 neighborhood centers
  - Government childcare subsidies and income-based scholarships provided to nearly 90% of SA families
  - Sheltering Arms Georgia Training Institute - trains more than 6,000 early childhood and family support professionals each year
- For this project, the study team recruited participants from seven SA centers across metro-Atlanta.

Design of the RCT

- This study was a single phase, concurrent mixed methods, randomized controlled trial design

- Quantitative data collection began in Summer 2012 and follow-up completed in Summer 2013

- Qualitative data collection began spring 2013 and preliminary analyses have just been completed

Groups

Participants randomly assigned to one of four groups:

(1) Control group (who received reading materials on parenting)

(2) Day care setting group (who received the *Milestone Moments* booklet in a SA parent resource room)

(3) Brief home visit group (who received the *Milestone Moments* booklet during a one-time home visit)

(4) SafeCare® group (who received the *Milestone Moments* during a six-session SafeCare® parent-child interaction module)

SafeCare®

- SafeCare is an evidence-based, training curriculum for parents reported or at-risk for child maltreatment

- SafeCare home visitors provide in-home training sessions for parents of children ages 0-5 in weekly visits of 1-2 hours over 18-20 weeks

- SafeCare modules focus on health, home safety, parent-child interaction, and problem solving

Measures

- Participant-completed surveys assessing:
  - General knowledge of child development
    - Knowledge of Infant Development Inventory (KIDI)
    - Knowledge of Infant Development Inventory – Preschool (KIDI-P)
  - Knowledge of their own child's development
    - Internally-developed survey
  - Identification of developmental concerns for their child
    - Internally-developed survey
  - Rate of follow-up regarding those concerns
    - Internally-developed survey
  - Risk for child maltreatment
    - Brief Child Abuse Potential Inventory

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Method: Criteria for Participation

- Parents or guardians of children between the ages of 2 months and five years

- Family incomes below the federal poverty level

- The target child did *not* have an identified disability or delay

- The target child scored above the cutoff on the *Ages & Stages Screening Questionnaire*

Recruitment

- Difficult!!
- Recruitment
  - Study staff placed in the Sheltering Arms centers at drop-off/ pick-up
  - Working closely with Family Support Staff
  - $25 per one-hour assessment session, $10 for the 20-minute *Milestone Moments* overview sessions, $25 for each one-hour SafeCare home visiting session, including the overview session

Retention

- Retention
  - Appointment reminder cards
  - Call day before *and* 1-2 hours before appointment
  - For post and follow-up: start calling week before appointment due
  - Text messaging worked well
- 'No-Shows'
  - Approximately 80% of participants failed to show up for one or more appointments; some more than once
  - Despite compensation, location choice, and numerous phone calls, etc. this population was difficult to retain

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Randomized Control Trial (RCT)

RCT Procedure (1)

- Data were collected at three time points
  - Baseline
  - 7 weeks (SafeCare program was 6 weeks long)
  - 19 weeks (12 weeks after post)
- At each time point, the participants completed the assessments on a laptop using ACASI, a voice administration software

RCT Procedure (2)

- After completing the baseline assessment:
  - The control group received the materials with no explanation
  - The day care group received the *Milestone Moments* booklet delivered following a standard script
  - The brief home visit group scheduled their visits within one week of baseline (ideally). During the home visit, participants received the *Milestone Moments* booklet with the standard script
  - The SafeCare® group scheduled their first home visits within one week of baseline. The participants received the *Milestone Moments* booklet at the end of the first visit with the standard script. The remaining five SafeCare® sessions occurred weekly following the first visit.

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RCT Data Analyses

- Logistic regression, generalized linear modeling, repeated measures ANOVA, chi-square tests, t-tests, and correlations were used to analyze the quantitative data

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Participants

- We recruited and received consent from 108 participants
  - 88 completed baseline and post assessments
  - 78 completed baseline, post, and follow-up
- Participants were predominantly
  - Mothers (88%)
  - Black/African American (86%)

Preliminary Results

- Results suggested that at post-assessment, parents reported:
  - Increased general knowledge of child development
  - Increased child-specific knowledge of child development
  - Reduced risk of child maltreatment
  - Increased level of comfort approaching a professional about a developmental concern
  - Fewer developmental concerns
  - Positive perceptions of the *Milestone Moments* booklet
- AND, most results maintained at the 12 week follow-up
- BUT, no strong effect of group, some indication that day care delivered information materials

General Knowledge of Child Development

- Parents of infants
  - trend toward significant interaction with increase in general parent knowledge and condition at post (p=.06) and follow-up (p=.06) (BHV > DC > SC > C at both times)

- Parents of preschoolers
  - greater knowledge at post (p=.02);
  - trend toward significant interaction with increase in general parent knowledge and condition at post (p=.08), diminishing at follow-up (p=.12)
  - DC > BHV > SC > C at post and follow up

Child-Specific Knowledge of Child Development

- Parents demonstrated greater knowledge of their own child's development at post (p<.001) and follow-up (p<.001); no difference by group or age of child

Risk for Child Maltreatment

- Parents had a lower risk for child maltreatment at post-assessment ($p<.05$), diminishing at follow-up ($p<.12$)
- No difference by group or age of child

Parent Level of Comfort with Professionals

- Parent comfort levels higher at post-assessment (p <.001), maintained at follow-up (p<.001)

- Parent comfort level over time varied significantly by group (p = .02), although post hoc tests (Bonferonni, REGWQ, Tukey, Duncan) did not reveal significant pairwise differences between groups

- Ordered by reported levels of comfort at post-assessment
  - SC > DC > BHV > C at post
  - BHV >SC > C > DC at follow-up

Perceptions of *Milestone Moments*

- There was a trend in differences between groups in terms of parent perception of the *Milestone Moments* booklet at post assessment ($p =.10$) (DC > SC > BHV)

Parent-Initiated Referral

- Rates of parent-initiated referral at post-assessment and follow-up did not differ across participant group or age of child

Identification of Developmental Concerns

- Rates of parent identification of developmental concerns were *lower* at post-assessment (p <.01)

- Rates of parent identification of developmental concerns at post-assessment did not differ across participant group or age of child

Trends in Follow-Up after *Milestone Moments* Booklet

- After receiving the *Milestone Moments* booklet, 7 parents in the treatment groups followed up with professionals, utilizing these methods for follow-up: phone call (1 parent), email (1 parent), took for a visit (2 parents), had child screened (2 parents), or enrolled in intervention services (1 parent)

- Among the 7 parents across the treatment groups who initiated a referral after receiving the *Milestone Moments* booklet, 5 were in the Day Care group, 1 in the Brief Home Visit group, and 1 was in the Safe Care group

Qualitative Study

Interview Procedures

- Semi-structured interviews were conducted with participants at the day care center in the parent resource room

- Interviews were audiotaped

- Participants were compensated for the interviews

- Interview protocol consisted of 14 questions inquiring about the parents' perceptions of the *Milestone Moments* booklet and their experiences in the study

Interview Participants

- Eligible participants were those who completed follow-up assessment in the RCT

- A total of 19 interviews were conducted
  - Day Care (n = 6)
  - Brief Home Visit (n = 6)
  - 6-Session Home Visit (n = 7)

Example Interview Questions

- What content did you like in the *Milestone Moments* booklet?

- What did you learn from the booklet?

- How did you use the information in the booklet after you received it?

- How do you feel about receiving the booklet/child development information at this time in your life?

- What improvements would you make to the *Milestone Moments* booklet?

Data Analysis

- To analyze the qualitative data, the constant comparative method of data analysis is being used as part of grounded theory methodology (Strauss & Corbin, 1990)

- This involves *open coding*, *axial coding*, and *selective coding* (Strauss & Corbin)

- Data analysis is still underway, but the preliminary results are reported below

Preliminary Theme (1)

Peer (Parent-to-Parent) Dissemination

I gave it away because it was a girl that was pregnant and she was so nervous and I said this will help you.

Well, I told a couple of my friends about it and let them look at the pamphlet, I did do that, and they were like "Wow, I didn't know my child is supposed to be doing this and that" ya know as far as what's in the pamphlet, but I spread the word, I let a couple of my friends look at it, cause I thought it was very informative.

I was able to tell her mom and give her information from this booklet to let her know that she needed to really reach out.

Preliminary Theme (2)

Receive Developmental Information Earlier

I wish I would have received this information when I was pregnant. Actually, that would have been more helpful.

Oh, I wish I had it earlier! Because she was… I mean, it had gotten to a point where it was distractin' for me. I was getting' stressed out and not knowing, because I honestly was goin' to her physician and goin', "Look. I think I need some help. Like she needs to be checked out."

Preliminary Theme (3)

Confirmed Typical Development

"...so I read the milestones, because I thought she was behind on a lot of stuff, but like reading it more...she's not...she's actually on time...everyone moves at their own pace....but she wasn't behind."

"I always thought certain ages like for instance ... for her age, she's at 3 and for me she's pretty advanced and for my thinking only to find out that she's pretty much average."

"Like I said....I've always thought of my children as advanced anyway...{chuckle} but...it just ...it kind of helps me keep my ego and pride I guess in check."

Preliminary Theme (4)

Empowerment

"It's a great tool, it's just a great way to educate and empower a parent...I know now that I can look back in the book and say 'ok, he's not counting on age, so I need to follow-up with somebody myself.' Versus waiting for somebody else to follow-up."

"and I learned that if it's something that I need, I'm not afraid to ask for assistance....cause I need help. If it's a local center, daycare or his doctor, I'm not afraid if there are any questions to ask."

"When he was 3-years-old and acting out I didn't go to the doctor and tell them. You know they'll ask you questions, 'Oh, is he so-and-so?' 'I'd say everything's fine.' That's what I said. B ut all I'm saying now is if we go in for his six-year check up and he's not doing this, I'm going to say 'Well, I read in the little milestone booklet that he should be doing this.'"

Preliminary Results (5)

Knowledge Change

Participants indicated that they learned about

- General developmental milestones

- Variation in child development

- Behaviors suggestive of developmental delay

- Pediatricians as a referral source when developmental concerns arise

Limitations/Cautions

- Participants' children had already been screened with Ages and Stages Questionnaire; children who had positive screens were excluded from the study

- Sheltering Arms has an ongoing referral process for developmental, behavioral, and mental health concerns for the children they serve

- Sheltering Arms may offer a powerful setting variable – one can be poor, but not necessarily be underserved

Next Steps and Conclusions

- Next steps
  - Finalize data analysis on post and follow-up data
  - Complete analysis of interview responses

- Conclusions
  - *Milestone Moments* booklets are helpful and memorable
  - No advantage to in-home delivery of the booklet
  - No advantage to delivery in the context of SafeCare
  - May be an advantage to information delivery in supportive child care setting

Contact Information

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End Notes

- ## Measures

  Knowledge of Infant Development Inventory (KIDI)

  Knowledge of Infant Development Inventory – Preschool (KIDI-P)
  Use requires permission of the author: David MacPhee, Colorado State University
  970-491-5503 (Office), macphee@cahs.colostate.edu

  Brief Child Abuse Potential Inventory (BCAP)

  Ondersma, S. J., Chaffin, M., Simpson, S., & LeBreton, J. (2005). The Brief Child Abuse
  Potential inventory: Development and validation. *Journal of Clinical Child and
  Adolescent Psychology, 34*, 301-311.

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