
Act Early Forum Webinar Series



Creative Ways to Reach Hard to Reach Populations

*Part 2 of 2: Addressing Literacy in Low Income Families
with “Learn the Signs. Act Early.”*

October 23, 2013

Webinar Overview

- Webinar Recording
 - Visit www.aucd.org/webinars
- Q & A
 - Please submit your questions throughout the webinar via the “question box” on your webinar dashboard. Questions will be answered following the presentation.
- Survey
 - Please complete the short survey at the end of the webinar!

Introductions



Catherine Rice, PhD, Epidemiologist, Behavioral Scientist, National Center on Birth Defects and Developmental Disabilities/Centers for Disease Control and Prevention

Introductions



Zolinda Stoneman, PhD, Director and University Professor, Institute on Human Development and Disability, University Center for Excellence in Developmental Disabilities, Education, Research and Science, University of Georgia



Daphne Greenberg, PhD, Professor and Principal Investigator of the Center for the Study of Adult Literacy, Georgia State University



Jonathan Campbell, PhD, Professor and Program Chair of School Psychology, University of Kentucky



Jessica Drennan, MSW, Oak Ridge Institute for Science and Education Evaluation Fellow, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention



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

Zolinda Stoneman,

Institute on Human Development & Disability/UCEDD

University of Georgia

Jonathan Campbell

University of Kentucky

Daphne Greenberg, Peggy Gallagher

Georgia State University

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 status 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)**

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**
 - Test utility of Theory of Planned Behavior for screening and monitoring
- **Develop recommendations and 'mock ups' of revised 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). This impacts:

- correspondence with schools**
- health**
- workplace**

Literacy and Health Education

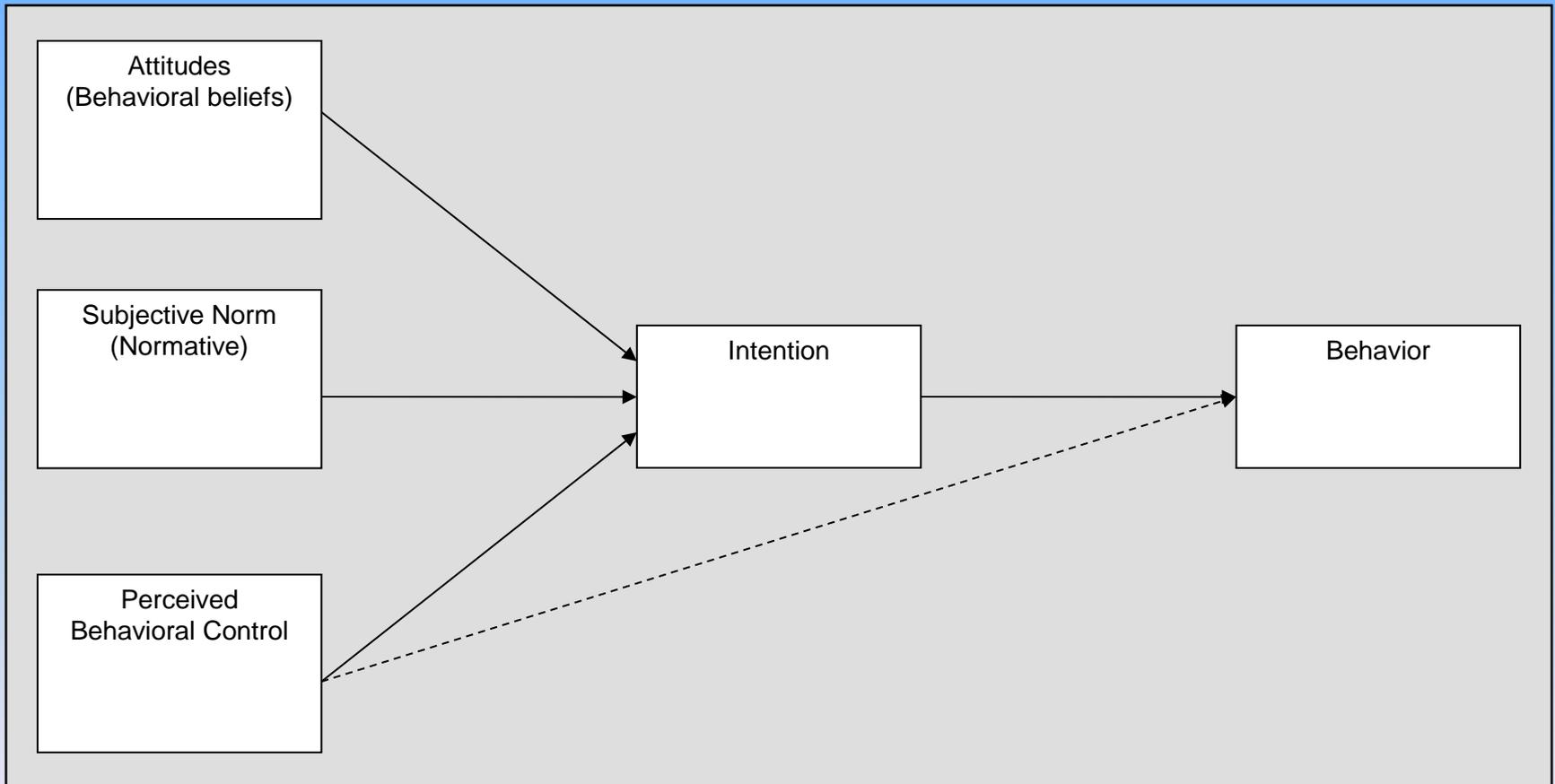
- **Lack of literacy skills major obstacle to effective health care communication**
- **Health education materials need to match reading skills of intended audience**
- **Research finds that most health education materials are written at a very high level**
- **Recommended level – 6th grade for 75% of population and 3rd grade for 90%**

TPB Survey Research

TPB Model Testing

- **TPB – general cognitive model to account for behavior – in our case monitor behavior and seek help**
- **Used widely in health promotion:**
 - **Bicycle safety helmet use;**
 - **Cancer screening;**
 - **Breast self-examinations;**
 - **HIV testing, among others.**
- **Model guides intervention efforts.**

Ajzen's (1991) Theory of Planned Behavior



Model Testing – Survey Description

- **Survey = 115 items:**
 - 7 demographic items
 - 30 knowledge questions about development
 - 23 knowledge questions about autism
 - 55 TPB items
- **Readability for items: 4th – 5th grade level.**
- **Piloted survey with 2 participants.**
 - Asked pilot participants to provide feedback: difficult to understand, redundant, etc.

Model Testing – TPB Survey

- Developed from focus group content.
- Examples of monitoring:

[Attitude: Belief strength]

1. Keeping up with Jon's development will help me talk with my child's doctor about him:

Disagree: 1 : 2 : 3 : 4 : 5 : Agree
Really Sort of Neither Sort of Really

X

[Attitude: Outcome evaluation]

2. Talking with Jon's doctor about him is a good thing:

Disagree: 1 : 2 : 3 : 4 : 5 : Agree
Really Sort of Neither Sort of Really

Model Testing – TPB Sample Items

Examples of acting on concerns:

[Subjective norm: Normative beliefs]

1. My mother thinks I should talk to my child's doctor if I am concerned about Jon's development:

X

[Subjective norm: Motivation to comply]

2. I really care what my mother thinks I should do:

Model Testing – TPB Sample Items

[Perceived behavioral control: Direct]

1. For me to keep up with Jon' s development is real easy:
2. If I want to, I can keep up with Jon' s development:

[Barriers]

1. I don' t trust my instincts enough to keep up....:
2. I don' t know how to keep up....:
3. I am afraid to keep up....:
4. I wouldn' t know how to talk to Jon' s doctor...

Main Points from Survey

- **Motor / language accuracy > social / play.**
- **Several early delays specific to autism may be missed:**
 - **Make believe play (~39% accurate)**
- **More knowledge related to fewer perceived barriers to monitoring development ($r = -.36$).**

Main Points from Survey

- **Perceived behavioral control good predictor of both monitoring and acting on concerns.**
- **For acting on concerns: attitudes, social norms, and perceived behavioral control predicted intentions to act.**
- **Include family – e.g., “It’s Better to Know” materials**
- **Targeting controllability of monitoring and acting important.**

Recommendations

- **Use a clear header at the top of all materials**
- **Parents were confused by the key phrase, “It’s time to change how we view a child’s growth”; use the word “development” instead of “growth”**
- **Use a larger font and allow more white space**
- **Use fewer words on each document**
- **Define the word “milestone” on each document**
- **Use numbers, not letters, for the CDC phone number**
- **Explain what is in the “free kit” – information, not samples of baby products or coupons**

LTSAE Materials Evaluated (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.

Positives

Attractive
Cute picture
Nice color and pattern
Type is good size

Negatives

Confusing message – think flyer is about teething or dental care
Terms “babbling”, “milestone” and “potential” hard to understand
Want more information about the “free kit”
Want a phone number to call



Promoting Developmental Milestones and Literacy Among Parents: An *Amazing* Children's Book and Strategic Partnerships

Jessica Drennan, MSW

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National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention

"Learn the Signs. Act Early." Team

National Center on Birth Defects and Developmental Disabilities

Division of Birth Defects and Developmental Disabilities, Prevention Research Branch



“Learn the Signs. Act Early.” Why?

- ❑ In the U.S., about 1 in 6 children aged 3-17 has a developmental disability
- ❑ About 1 in 88 children has an autism spectrum disorder
- ❑ Many children with a developmental disability are not identified until after entering school
- ❑ Early intervention (before school age) can have a significant impact on a child’s ability to learn new skills and reduce lifetime costs

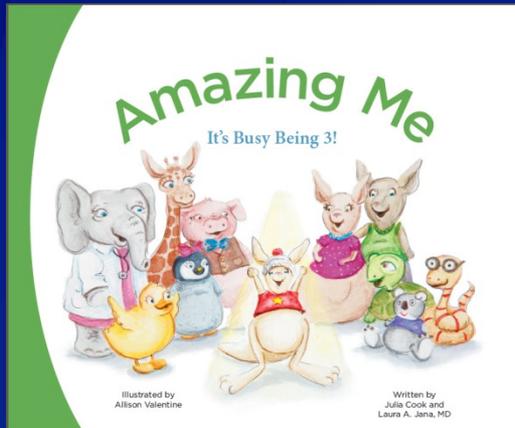


CDC's "Learn the Signs. Act Early."

- ❑ Aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need as early as possible.
 - Health Education Campaign
 - Act Early Initiative
 - Research and Evaluation



Reaching Parents through a Children's Book



- ❑ New, creative health communication strategy
- ❑ Appeal to/reach parents who might be missed by traditional health communication products or strategies
- ❑ Provides an opportunity to promote reading with young children
- ❑ Opens the door to new partnerships and outreach strategies



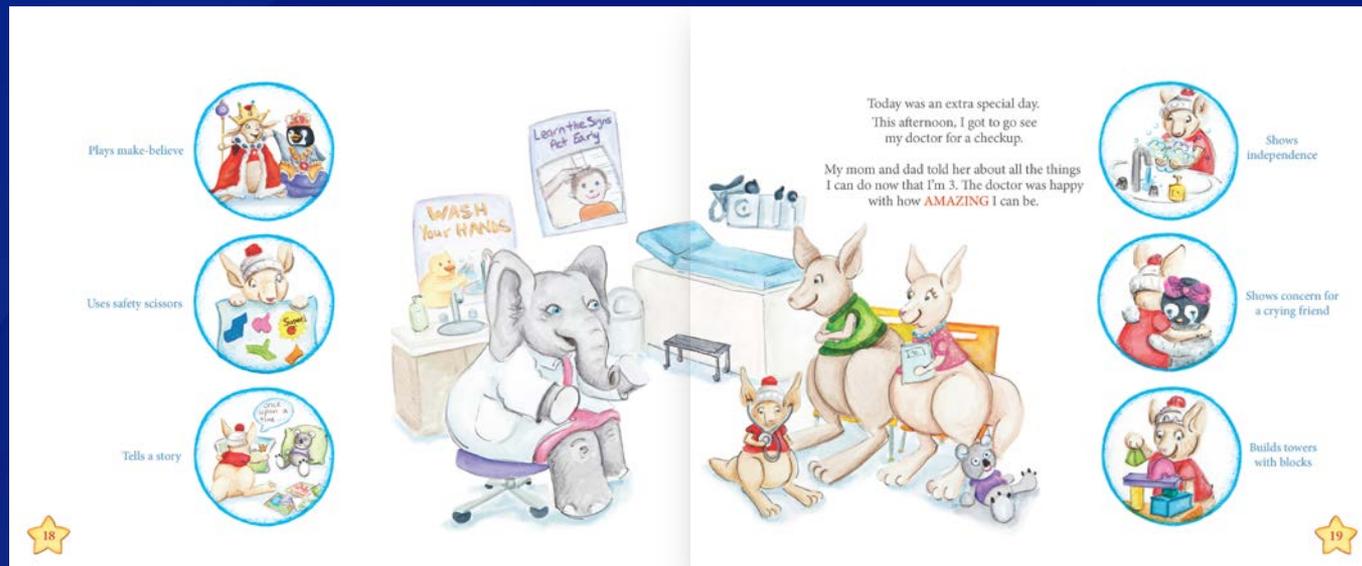
Amazing Me-It's Busy Being 3!

- ❑ Story of Joey, a 3-year-old kangaroo enjoying a typical day in his life
- ❑ Throughout, Joey exhibits “milestone moments”
- ❑ “Milestone moments” are called out to mom or dad
- ❑ Parents are encouraged to look for these milestones in their own child



Not Just a Children's Book

- ❑ Introduces developmental monitoring through “Milestone Moments”
- ❑ Encourages active reading; child participation
- ❑ Models key parent behaviors
- ❑ Provides parent tools



Using Strategic Partnerships to Reach Parents

□ Printing

Partnered with Reckitt-Benckiser (Lysol)* to have 100,000 copies of *Amazing Me!* printed

□ Distribution

Partnered with Reach Out and Read to distribute books to 250 health clinics in the United States.



*Acknowledgement of corporate supporters does not imply endorsement of these companies or their products.

The Importance of Strategic Partnerships

- ❑ Organizations and people have to do more with less
- ❑ Partnerships help to disseminate to audiences that are not reachable by traditional channels
- ❑ Matching and/or complimentary missions and goals for a successful partnership

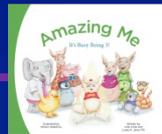


Strategic Partnering with Reach Out and Read

- ❑ Evidenced-based model to promote early literacy
- ❑ Docs encourage reading and provide a free, age-appropriate book at every well-child visit
- ❑ Practices serve low-income families
- ❑ Reach ~500,000 3-year-olds annually
- ❑ www.reachoutandread.org



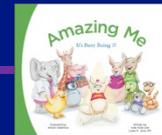
How We Reach Parents: A Distribution Model



300 books per clinic



250 ROR clinics



75,000 children reached



The Evaluation of the Distribution and Reach of *Amazing Me!*: Two Phases

□ Phase I (2012-2013) Goals:

- Determine if ROR practices have distributed *Amazing Me!*
- Measure how many books were given to the appropriate audience (i.e., parents of 3-year-olds)
- Assess barriers, if any, to distribution
- Examine overall distribution experiences

□ Phase II (2013-2014) Goals:

- Gather parent feedback about *Amazing Me!*
- Determine the influence of the book on parents' awareness, attitudes, and self-efficacy regarding monitoring developmental milestones



Evaluation Findings: Overview of Clinic Responses

Phase I: Web-Based Survey to ROR Clinics

- ❑ 85% gave the book to only 3-year-olds
- ❑ 84% reported that the doctor or nurse reviewed or discussed it with parents
- ❑ 75% thought their experience distributing the book facilitated more discussion with parents on development and milestones
- ❑ 82% reported the book was received well by parents
- ❑ 97% would like to continue to distribute the book



Evaluation Findings on Reaching Parents

Phase I: Web-based survey to ROR clinics

- ❑ 91% of clinics were able to distribute at least two-thirds of their supply in less than six months
- ❑ Established Reach Out and Read distribution method
- ❑ Reach Out and Read is reporting that clinics want more copies

Phase II: Expansion to additional ROR and Non-ROR clinics and parents

- ❑ Next steps are taking place now!



“This is a GREAT book. The parents love this book, the kids love it and the providers love it. It is one of our favorites.”

-Clinic Administrator

Thank You!

www.cdc.gov/actearly

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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

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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.

National Center on Birth Defects and Developmental Disabilities

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Q & A

- Ask a question!
 - Type your question in the “question box” on your webinar dashboard.
 - The moderator will read the question.

Thank You!

- Learn more about Act Early!
 - www.cdc.gov/actearly
 - www.aucd.org/actearly
- Questions about the webinar?
 - Email Tory Christensen (tchristensen@aucd.org)

Please take a few minutes to complete the survey!