Facilitating Earlier Identification of Autism Spectrum Disorders: Role of Speech-Language Pathologists

PRESENTED BY:
LILY NALTY, MA, CCC-SLP
GEORGINA PEACOCK, MD, MPH
MARThA ALEXANDER, MA, MPH, CCC-SLP

INTRODUCTION

Agenda

1. Introduction
2. Need for Earlier Identification of Autism Spectrum Disorders (ASD) and Role of SLPs
3. Methodology
   ▪ Results of literature review and landscape audit (existing resources)

Agenda cont’d

3. Methodology, continued
   ▪ Development of national survey
4. Findings
5. Study Strengths and Limitations
6. Recommendations
7. Questions
8. Additional Recommendations and Considerations
   ▪ Health literacy considerations
   ▪ CDC campaign
9. Audience Recommendations and Discussion
   ▪ Discussion of methods for SLPs to facilitate earlier identification of ASD

Session Outcomes

• By the end of the session, learners will be able to:
  ○ Explain how SLPs working with young children currently help families participate in the process towards ASD diagnosis
  ○ Describe the role of SLPs in helping families explore or reach an earlier diagnosis of ASD
  ○ Discuss the ways that SLPs can facilitate recommendations from this study’s research to facilitate earlier identification of ASD
Need for Earlier Identification

- Affects 1/100 to 1/300 children
- Is the second most frequently occurring serious developmental disability
- Presents an urgent public health concern and concerted and substantial response
  - CDC/AUCD Collaborative Researcher Award (CRA)
    - (e.g., Rice, 2007; Van Naarden-Braun et al., 2008; Kogan, 2009)
Primary Aim: To develop methods for supporting the role of Speech-Language Pathologists (SLPs) in helping families “Act Early” to navigate systems for a diagnosis of Autism Spectrum Disorders (ASD)

Primary Research Questions:
1. How do SLPs working with young children 0-6 years of age currently help families participate in the process towards ASD diagnosis?
2. What additional ways can SLPs be supported to help families explore/reach a diagnosis of ASD?

Initial Review of the Literature
The problem

- ASD is lifelong, responds to intervention
- Diagnosis has been 4.5 and 5.5 years of age (Rice, 2007)

Initial Review of the Literature
The problem

- Concerns often reported before 24 mos
- Early indicators observed by 18 mos
- Initial evaluation to diagnosis is 13 mos (e.g., Wetherby, 2009; Rice, 2007; Chawarska et al., 2007; Wiggins et al., 2006; National Research Council, 2001)

Initial Review of the Literature
The problem

- Early intervention makes a difference (e.g., Harris and Handleman, 2000; National Research Council, 2001; Landa, 2007)
- Identifying, diagnosing, and beginning intervention later

Initial Review of the Literature
The problem

- Communication and language are one of the most frequent areas of delay (Hebbeler et al., 2007)
- Deficits in social aspects of verbal/nonverbal communication are potential first markers (Wetherby, 2009; ASHA, 2006)
Initial Review of the Literature

The problem

- Language and communication deficits may be labeled “speech” delays (Johnson et al., 2007)
- SLPs may be one of the first to receive concerns
- SLPs are positioned to help guide families

Facilitating Earlier Age of ASD Diagnosis

- Involving and educating families leads to earlier referral, diagnosis, and intervention
- SLPs must be prepared with current, readily-useable evidence-based information (ASHA, 2006)

Facilitating Earlier Age of ASD Diagnosis

- Research emerging
  - Steps to earlier identification
    - Early indicators and screening tools
    - Listen, screen (18 and 24 mos, American Academy of Pediatrics), refer, support

METHODOLOGY

Methods (Formative Research Activities)

Step 1: Expand Literature Review
Step 2: Conduct Landscape Audit

Results of Literature Review:

- little related to what SLPs do now with young children (0-6 yrs old) with potential ASD
Methods

Results of Landscape Audit

- Websites for families, physicians, childcare providers
- Websites relevant to SLPs

Methods National Survey: what happens now, and what is recommended, to help determine how best to support SLPs
**Methods**

**Step 3: Develop National Survey**

- **Develop questions**
  - ASHA (2006), Guidelines for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span
  - Surveys: CDC, National Early Childhood Technical Assistance Center (NECTAC) survey of Part C Coordinators (2008, 2009), Survey of school SLPs (Schwartz and Drager, 2008)

**Methods**

**Step 3: Develop National Survey, cont’d**

- **Contact dissemination sources**
  - ASHA, NECTAC, states’ speech-language-hearing associations
- **Explore sources for online surveys**
  - Unlimited number of respondents, tracking, de-identification, data analysis features

---

**Methods**

**Step 4: Analyze results** from 2073 respondents (convenience sample)

---

**FINDINGS**

**2073 Participants – Yrs of Experience**

- CFY: 2.2% (45)
- 1-5 years: 15.4% (316)
- 6-10 years: 18.0% (368)
- 11-20 years: 27.8% (573)
- 21+ years: 35.3% (722)

**2073 Participants - Ages**

- 25-34: 27.4% (557)
- 35-44: 27.8% (573)
- 45-54: 16.9% (345)
- 55-64: 10.9% (218)
- 65+: 1.2% (24)
2073 Participants – Primary Job Role

90%
(1,822)
Service providers

2073 Participants - State

What do you do when working with young children six years of age and younger?

- Types of information families request
- SLP activities when autism is suspected
- SLP activities when evaluating young children

What SLPs do now – key points

Many SLPs do not use published screeners to detect children with potential ASD

Consistent across yrs experience, age groups, & rural/urban/suburban areas

Consistent for all primary work settings, except college/university sites who did use published screeners

Screening is important for early identification
When I suspect autism in a child, I usually refer the child and family to (select all that apply):

- Developmental pediatricians (55.6% (1,087))
- Part C systems (53.6% (1,048))
- Family pediatricians/physicians (44.6% (306))
- • Consistent across variables
- • Need to know where to refer

When autism is a concern, I provide the following types of support to families (select all that apply):

- 79.7% (1,639) Coordination with other professionals
- 61.6% (1,267) Informational support from family and friends
- 80.8% (1,664) Ongoing support with family and friends for the first year
- 73.7% (1,516) Two years of follow-up

SLPs felt least prepared to:

- Discuss current evidence about autism with families
- Select screening tools for autism
- Help families reach a diagnosis of autism
- Explain information about autism to families of differing cultures
- Access easy to read and appropriate resources about autism to give to families

How prepared do you feel to do the following?

- Assess children with potential autism
- Communicate with families about autism

Preparation – other key points

Many SLPs did not feel prepared to: select or use screening tools for autism (65.55-56.65%), and to explain information about autism to families of differing cultures (61.47%). Exceptions:

- 1-5 years experience and from certain community settings (daycare, Head Start, speech/hearing centers) felt least prepared to: discuss current evidence about autism with families, help families reach a diagnosis, and access easy to read and appropriate resources about autism to give to families
- SLPs in rural areas felt least prepared to: access easy to read and appropriate resources about autism to give to families
- SLPs in their CF year identified the most needs related to ASD
Information SLPs would like to have

<table>
<thead>
<tr>
<th>Top recommendations</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current evidence in the field of autism</td>
<td>78%</td>
</tr>
<tr>
<td>Information for families about autism that is easy to read and understand</td>
<td>77.5%</td>
</tr>
<tr>
<td>Information about screening and screening tools for autism</td>
<td>76%</td>
</tr>
<tr>
<td>Methods for explaining information about autism to families of differing cultures</td>
<td>70.6%</td>
</tr>
</tbody>
</table>

Information Needs – other key points

Graduate students, SLPs 1-5 yrs experience, preferred most of the information
- primarily on speech/language indicators of ASD and expected role of SLPs in helping families reach earlier diagnoses of ASD

SLPs in rural areas (81.2%) and SLPs in family homes (77.9%) wanted information
- primarily for families that is easy to read and understand

How often do you acquire autism information from these sources now?
- Hard copy products such as brochures, fact sheets
- Internet/Web
- On-line networks and forums such as: Podcasts, webinars, Facebook, Blogs, Wiki, Myspace
- Emailed updates such as: enewsletters, listservs
- CDC’s “Learn the Signs. Act Early.” campaign

How SLPs Acquire Information Now

- Consistent across years experience, age groups, & rural/urban/suburban area
- Exceptions:
  - university settings and SLPs with experience (21 yrs+) who also used other options such as journal articles
  - SLPs 1-5 yrs experience who most often also used textbooks
### How SLPs prefer to receive information

1. Professional meetings/conferences: 97.03%
2. Colleagues/Specialists: 96.13%
3. CDC’s “Learn the Signs. Act Early.” campaign: 94.74%
4. Hard copy products such as brochures, fact sheets: 94.17%
5. Internet/Web: 93.41%
6. Emailed updates such as enewsletters, listservs: 83.30%
7. Journal articles: 79.83%
8. Pre-service/university graduate level training: 76.88%
9. Textbooks: 56.03%
10. Online networks and forums such as: Podcasts, webinars, Facebook, Blogs, Wiki, Myspace: 50.76%

### Comments

Re what takes place when autism is suspected:
- Some settings discourage screening for ASD
- SLPs report a wide variety of tools used for screening
- Some SLPs immediately institute family training

SLPs preferred information or resources about:
- What to do when families may not be ready to hear about potential ASD
- In other languages
- Payment and reimbursement
- Advocacy strategies

SLPs preferred information or resources about:
- Local resources: professionals specializing in autism, educational or support groups
- Appropriate interventions to share with families and others, such as, naturalistic, dietary, to improve reading comprehension

Preferred methods for receiving information:
- Online workshops or trainings
- Face-to-face workshops or training institutes (including regional or local)
- Web casts (webinars or podcasts), but not Facebook or Blogs
- Graduate level coursework and hands-on experience
STRENGTHS AND LIMITATIONS

Limitations

- Preliminary research study
- Convenience sample
- Can not monitor for ineligible respondents
- Questions did not differentiate SLP practices when working with children of different ages
- Question related to use of social media for dissemination of professional information grouped too many types of forums (e.g., facebook and webcasts)

Strengths

- Focused on SLPs working with young children 0-6 years of age
- Representative of ASHA membership
- Response rate
- Allows targeted follow-up support based on current practices, preparation level, demographic need, etc.

- Focused on what SLPs do now, preparation level, and preferences vs focus on knowledge and skills
- Questions adapted from ASHA, NECTAC, CDC, and Schwartz and Drager (2008), allow comparisons
- SLPs learned about the CDC's "Learn the signs. Act early campaign." website

RECOMMENDATIONS

1. How do SLPs working with young children 0-6 years of age currently help families participate in the process towards ASD diagnosis?
2. What additional ways can SLPs be supported to help families explore/reach a diagnosis of ASD?

QUESTIONS
A doctor gives you this handout...

Your naicisyhp has dednemmocer that you have a ypoconoloc. Ypocsonoloc is a test for noloc recnac. It sevlovi gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.


What is the problem?

“Our nation’s low health literacy is a threat to the health and well being of Americans and to the health and well being of the American healthcare system.”

Richard Carmona, Former U.S. Surgeon General

Definitions: Health literacy

- “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

Healthy People 2010

Health literacy is...

- Reading
- Writing
- Speaking
- Listening
- Numeracy
- Cultural and conceptual knowledge
What are skills we need for health?

- Understand food labels and make decisions based on them
- Make a decision about whether to participate in or have your child participate in a clinical study based on informed consent forms
- Find the Speech & Hearing Clinic in a large and busy hospital

Risk factors for limited health literacy

Persons who are:
- Older
- Are poor
- Have limited education
- Part of a minority ethnic group
- Recent immigrants and have limited English proficiency

Literacy and health knowledge

- Persons with high blood pressure were less likely to know how weight loss and exercise could lower BP
- Persons with diabetes were less likely to know symptoms of hypoglycemia
- Persons with asthma were less likely to know how to use an inhaler

From AMA Health Literacy Manual

Literacy and health outcomes

- Limited literacy and limited understanding of health concepts are associated with poorer health outcomes
- Occurs in all socioeconomic groups

From AMA Health Literacy Manual

Literacy and healthcare costs

- Annual healthcare costs of Medicaid enrollees: $3,000
- Annual cost for Medicaid enrollees with limited literacy: $13,000
- $30 billion to $73 billion in 1998 estimated to be due to inadequate health literacy
- 2.3% – 7.6% of personal health care expenditures estimated to be due to inadequate health literacy

From AMA Health Literacy Manual

Conceptual Model of Health Literacy

Interventions

- Educational and communication media
- Verbal communication strategies
- Systems change

Example: Hand Washing Chart

When To Wash Your Hands

After Using Toilet  Before Eating  After Sneezing, Coughing or Sneezing

www.photonovela.com

www.photovoice.com
Example: Hand Washing Chart

How To Wash Your Hands

1. Wash Hands
2. Put Soap on Hands
3. Rub Hands Together for 20 Seconds
4. Rinse Hands
5. Dry Hands
6. Turn Water Off

Hand Washing Chart

- Created by North Dakota Disability Health Project, Minot State University Center of Excellence.
- Purpose:
  - Provide information on preventative measures that can be used to stop spread of germs through health fairs
- Target Audience:
  - Individuals with Developmental Disabilities

Assessing existing products

- Assessing Suitability of Materials
  - www.hsph.harvard.edu/healthliteracy/doak4.pdf

Interventions

- Educational and communication media
- Verbal communication strategies
- Systems change

Ask Me 3 Communication

- 3 Questions:
  - What is the main problem?
  - What needs to be done?
  - Why is it important to do this?
- Purpose:
  - Promote communication between health care providers and patients in order to improve health outcomes

Example: Ask Me 3

<table>
<thead>
<tr>
<th>3 Questions</th>
<th>How Do I Remember What to Do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the main problem?</td>
<td>1. What do I need to do?</td>
</tr>
<tr>
<td>2. What needs to be done?</td>
<td>2. What is the plan?</td>
</tr>
<tr>
<td>3. Why is it important to do this?</td>
<td>3. How do I execute this plan?</td>
</tr>
</tbody>
</table>
**Ask Me 3 Communication**
- Patient Education Program
- Developed by Partnership for Clear Health Communication (Pfizer and National Patient Safety Foundation)
- [www.npsf.org/askme3/](http://www.npsf.org/askme3/)

**Interventions**
- Educational and communication media
- Verbal communication strategies
- Systems change

**Example: Medication Chart**
- Developed by IRIS Media Inc., Educational Media, as part of project *Working with Parents with Cognitive Limitations*
- Purpose:
  - Provide prescription medication instructions in an easy to understand way
  - Used by physicians, nurses, and pharmacists with patients

**Medication Chart**
- Developed by IRIS Media Inc., Educational Media, as part of project *Working with Parents with Cognitive Limitations*
- Purpose:
  - Provide prescription medication instructions in an easy to understand way
  - Used by physicians, nurses, and pharmacists with patients

**Sample Plan for Improving Health Literacy in a Community Health Organization**
- [http://www.health.gov/communication/literacy/sampleplan.htm](http://www.health.gov/communication/literacy/sampleplan.htm)

**National Efforts**
- IOM Report
  - *Health Literacy: Prescription to End Confusion*
- Healthy People 2010
  - [www.healthypeople.gov/](http://www.healthypeople.gov/)
  - [www.health.gov/communication/healthypeople/default.htm](http://www.health.gov/communication/healthypeople/default.htm)
- Healthy People 2020 draft objectives
- National Action Plan to Improve Health Literacy: Under development
Goal of public health literacy

"An informed, motivated public with the skills and resources to make positive choices that enhance individual and community health."


Health Literacy: What Can Speech-Language Pathologists Do?

• ASHA’s vision: “Making effective communication, a human right, accessible and achievable for all”
• Educate yourself, other health professionals, policy makers, stakeholders, and consumers about health literacy
• Apply the principles of health literacy in your work
• Conduct research
• Apply research in interventions


CDC’s “Learn the signs. Act early.”

• Educational and communication media
• Verbal communication strategies
• Systems change

2002 Mandate from Congress

...to establish a national awareness and education program that will widely disseminate information regarding autism identification and diagnosis to both families and health care providers as authorized by Sec. 103 of the Children’s Health Act of 2000. This program should be administered and piloted in partnership with voluntary organizations already working in the autism community.
CDC’s “Learn the signs. Act early.”

- Early years focused on “Learn the signs.” to help increase awareness of developmental delays including ASD
- Expanded to help parents learn how to “Act early.”

The campaign reached out to healthcare providers and early educators
- Exploring approaches to include Speech-Language Pathologists (SLPs)
  - Young children with developmental delays often have speech, language, communication concerns

The Messages

- "Early identification is key"
- "The earlier a delay is recognized the more can be done to help"
- "You know your child best"
- "Milestones monitor more than just the physical—how a child plays, learns, speaks, and acts offers important clues about his development"
- "Most delays are not outgrown, with help a child can reach her full potential"

Baby Steps Video: [www.cdc.gov/CDCTV/BabySteps](http://www.cdc.gov/CDCTV/BabySteps)

Health Communication Campaign: One of a 3-Pronged Approach

1. “Learn the Signs. Act Early.”
   - Increase awareness, knowledge, and desired behaviors
2. “Act Early” Regional Summits
   - Facilitate communication/coordination among systems that identify, intervene, and care for children with developmental disabilities
3. Research & Evaluation
   - Identify areas for strengthening and test innovative strategies for campaign implementation

Campaign Materials

<table>
<thead>
<tr>
<th>Educational</th>
<th>Promotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Print</td>
<td>• Print</td>
</tr>
<tr>
<td>• Web</td>
<td>• TV/Radio</td>
</tr>
</tbody>
</table>

Educational Resources: Print

FREE Resource Kits
- Health Professionals
- Parents
- Early Educators
- Outreach

[www.cdc.gov/actearly](http://www.cdc.gov/actearly)
click on “Free Materials”
Health Care Professional Resource Kit
- Stand with 200 Informational Cards
- Set of 15 Fact Sheets
- Small Posters (3)

Parent Resource Kit
- Growth Chart (1)
- Informational Card (1)
- Set of 8 Fact Sheets

Early Educator Resource Kit
- Flyers for Parents (50)
- Growth Charts (3)
- Small Posters (3)
- CD-ROM
  - Fact sheets
  - Milestones checklists
  - Tips for talking to parents

Spanish-Language Information
- Resource kits (all materials double-sided with English on one side, Spanish on the other)
- Website – www.cdc.gov/pronto
- 1-800-CDC-INFO

Educational: Web
- Printable Milestones Checklist
- Interactive Milestones Chart
- “Baby Steps” Video
- “If You’re Concerned…”
- ECard
- Positive Parenting Tips

Educational: Web, cont’d
- Health Professional Resources
  - (M-CHAT, coding for reimbursement, etc)
- “Go Out & Play! Kit” for Early Educators
- Website Linking Instructions
- Campaign Connections
- Ideas for Getting Involved
Promotional:  
PSAs for Print, TV, Radio  
- Print  
- Television (30-second; English only)  
- Radio (60-second; Eng & Span)  

Other Promotional Materials:  
- Banner Ads  
- Exhibit Tools  
- Milestone Fun Facts  

Campaign Partners:  
Collaborators in Campaign Development  

Partners: Collaborators in Campaign Implementation  
- HRSA/Maternal and Child Health Bureau  
- Association for University Centers on Disabilities  
- Easter Seals  
- The Commonwealth Fund  
- Cooperative Extension Program  
- Early Head Start/Zero to Three  
- Indian Head Start  
- National Association of Child Care Resource Agencies  
- ... and many more!  

Visit Us at the ASHA Conference  
“Learn the Signs. Act Early.”  
Booth Number: 413
**Recommendations and Discussion**

- Recommendations
- Needs
- Barriers
- Next steps

**Primary Survey References**


http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm.


National Early Childhood Technical Assistance Center (NECTAC) Screening and Early Identification, Queries, updated report downloaded 11-09, http://www.nectac.org/topics/autism/eidautism.asp

**Recommendations and Discussion**

- Health Literacy Resources: Literacy
  - 2003 NAAL http://nces.ed.gov/naal/
  - National Institute for Literacy www.nifl.gov
  - NIFL list servs http://www.nifl.gov/lincs/discussions/discussions.html

- CDC health literacy site http://www.cdc.gov/HealthMarketing/healthliteracy/
  - Free online training course: Health Literacy for Public Health Professionals

- Health Resources and Service Administration (HRSA) http://www.hrsa.gov/healthliteracy/training.htm
  - Free online training course: Unified Health Communication 103: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency

**Early Identification Resources**

CDC’s “Learn the signs. Act early” website http://www.cdc.gov/ncbddd/actearly/index.html


National Early Childhood Technical Assistance Center website page on Early Identification of ASD in Young Children http://www.nectac.org/topics/autism/eidautism.asp

First Words Project website, model early identification and intervention program based in the Department of Communication Disorders at Florida State University. http://firstwords.fsu.edu/

Autism Society of America website http://www.autism-society.org/site/PageServer

**Primary Survey References, cont’d**


**Health Literacy Resources**

- Health Literacy Resources
  - Recommendations
  - Needs
  - Barriers
  - Next steps

- Primary Survey References
  - Recommendations
  - Needs
  - Barriers
  - Next steps

- Health Literacy Resources: Literacy
  - 2003 NAAL http://nces.ed.gov/naal/
  - National Institute for Literacy www.nifl.gov
  - NIFL list servs http://www.nifl.gov/lincs/discussions/discussions.html

- CDC health literacy site http://www.cdc.gov/HealthMarketing/healthliteracy/
  - Free online training course: Health Literacy for Public Health Professionals

- Health Resources and Service Administration (HRSA) http://www.hrsa.gov/healthliteracy/training.htm
  - Free online training course: Unified Health Communication 103: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency
Resources: Health literacy

- Harvard SPH
  [http://www.hsph.harvard.edu/healthliteracy/index.html](http://www.hsph.harvard.edu/healthliteracy/index.html)

- Pfizer Health Literacy

- AMA Health Literacy

Resources: Plain language

- Plain Language.gov

- NIH Plain Language Initiative

- Center for Plain Language

More information is available at
[www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)

Speaker Contact Information:

Georgina Peacock
gep3@cdc.gov

Lily Nalty
Lily.Nalty@uscmed.sc.edu

Martha Alexander
mea3@cdc.gov