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

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The findings and conclusions in the presentation have not been formally disseminated by the Centers for Disease Control and Prevention. They do not represent and should not be construed to represent any agency determination of policy.
CRA 2009, 2010, Involving allied health care professionals in helping parents navigate systems for ASD diagnosis

Formative Research/Primary Aim: 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 toward ASD diagnosis?

2. What additional ways can SLPs be supported to help families explore/reach a diagnosis of ASD?
Background

- Average age of diagnosis - 4 1/2 yrs
- Concerns - often reported before 24 mos
- Early indicators - observed by 18 mos

- Early intervention makes a difference; identifying, diagnosing, and beginning intervention later
- Corresponds to under-identification of children with developmental disabilities (Note: Wetherby, 2009)

(e.g., CDC, MMWR 2009;58(No. SS-10); Wetherby et al., 2009, 2008; Rice, 2009, 2007; Chawarska et al., 2007; Wiggins et al., 2006;
### Key Issues

- Speech, language, and communication delays - deficits in social aspects of verbal/nonverbal communication are potential first markers of ASD (Wetherby, 2009; ASHA, 2006)

- Speech, language, and communication deficits - may be labeled “speech” delays (Johnson et al., 2007)

- SLPs may be one of the first to receive concerns and 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)
- Research emerging
  - Steps to earlier identification
    - Early indicators and screening tools (ASD-specific and broadband) (e.g., Communication & Symbolic Behavior Scale DP behavior sample for < 2 yrs)
    - Listen, screen (18 and 24 mos, American Academy of Pediatrics), refer, support
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?

Literature Review: Little related to what SLPs do now with young children (0-6 yrs) with potential ASD
- Need for national survey

Landscape audit: Websites and products for families, physicians, childcare providers
- Websites relevant to SLPs
Fact Sheets, Resource Kits, Growth Chart, and more...

CDC has FREE materials for parents, healthcare providers, and childcare providers. All materials are printed with English on one side and Spanish on the other.

To view, print, or order materials click on one of the following links. Questions? Please contact CDC Info
The FIRST WORDS® Project is a longitudinal research investigation in the Autism Institute in the College of Medicine at Florida State University. Our major goal is to identify early red flags of developmental language disorders, autism spectrum disorders, and other communication delays in children under 24 months of age. Through our research findings, we aim to improve screening tools and early detection of communication disorders by maximizing the role of the family, which will help families obtain intervention services sooner.

The FIRST WORDS® Project has received support for research from the National Institutes of Health, Institute on Deafness and other Communication Disorders and Eunice Kennedy Shriver National Institute of Child Health & Human Development; the Centers for Disease Control and Prevention; the U.S. Department of Education, Office of Special Education Programs and Institute of Education Sciences; the Jessie Ball duPont Fund, Jacksonville, Florida; the Phillips Endowment, Todd and Annie Trimmer; and Delta Airlines.
Our Mission

First Signs is dedicated to educating parents and professionals about the early warning signs of autism and related disorders.

With developmental, behavioral, and learning disabilities on the rise, there is much that remains poorly understood, from cause to cure. However, there is one widely accepted fact: early and appropriate intervention is essential for children with autism spectrum disorders — and the sooner the better.

What's new and worth knowing about...


[Read more information and reviews] [Read an excerpt] [Read the Table of Contents] [Order online]

Autism Resources

... the Child Neurology Society Consumer Information on Autism Bilingual Autism Resource Guide (from ASD from A to Z) Interactive Autism Network Networking Opportunities
Source: ASHA Web Site - Restricted
http://www.asha.org/slp/clinical/autismresources.htm - 29 KB
Details

Autism (Autism Spectrum Disorders)
General information about autism: symptoms, diagnosis, treatment, and additional resources.
Source: ASHA Web Site
http://www.asha.org/public/speech/disorders/Autism.htm - 30 KB
Cached | Details

Autism Online: Conference Faculty
Home > Autism Online Register through the ... of language development in children with autism, differentiation of autism spectrum disorders, and effectiveness of ...
Source: ASHA Web Site
http://www.asha.org/events/autism-conf/AutismFaculty.htm - 43 KB
Cached | Details

April 2 is World Autism Day
April 2 is World Autism Day and ASHA offers a wide range of information about communication disorders, including autism spectrum disorders. (March 31, 2009)
Source: ASHA Web Site
Cached | Details

Autism Spectrum Disorders Assessment
Early Identification of ASD in Young Children


The Centers for Disease Control and Prevention (CDC), in collaboration with national partners, is hosting a public awareness campaign entitled Learn the Signs, Act Early. The campaign is meant to help parents and child care providers learn more about early childhood development, including potential early warning signs of autism and other developmental disabilities. Building on the success of this campaign, in February 2008 and March 2008, selected states were invited to attend Act Early Regional Summits for the purpose of developing Act Early Plans to enhance their capacity to identify children with ASD earlier and provide evidence-based intervention.

Autism Speaks, Florida State University's FIRST WORDS Project and First Signs have developed a Web-based ASD Video Glossary for parents of children suspected of or recently diagnosed with autism and for professionals who do not have experience in diagnosing young children with Autism Spectrum Disorders (ASD). It contains hundreds of video clips contrasting behaviors that are red flags for ASD with behaviors that are typical.

A promising practices report from the Centers for Medicare and Medicaid Services entitled California – Single Process for Diagnosis and Service Delivery (2007) describes one-stop clinics in California that have been established to diagnose ASD and start services as early as possible. Findings from an evaluation of these clinics show a four-month reduction in the average age of ASD diagnosis.

A Webcast entitled Screening for Autism and the Management of Neurobehavioral Comorbidities: A Primer for General Pediatricians (2007) has been released by the Advanced Studies in Medicine Program at Johns Hopkins University in collaboration with Autism Speaks. It is meant to help pediatricians and other health professionals better understand the signs and symptoms of autism. It is not meant to be used by parents or other caregivers to diagnose autism in their own children.
Methods

- **Developed National Survey**
  - Current literature
  - Survey developed based on: CDC surveys, National Early Childhood Technical Assistance Center (NECTAC) survey of Part C Coordinators (2008), Survey of school SLPs (Schwartz and Drager, 2008)
    - Critical review of survey from: ASHA, CDC, NECTAC, colleagues, IRB

- **Disseminated**
  - ASHA, NECTAC, states’ speech-language-hearing associations

- **Electronic survey**

- **Analyze results from 2073 respondents (convenience sample)**
PRELIMINARY FINDINGS

WHO PARTICIPATED?
2073 Participants – Yrs of Experience

- 21+ years: 35.1%; 722
- 11-20 years: 27.8%; 573
- 6-10 years: 18.9%; 388
- 1-5 years: 15.4%; 316
- CFY: 2.2%; 45
Gender

Gender Distribution:
- Female: 100%
- Males: 0%

(Chart showing the comparison between ASHA and Survey data for Gender.)
2073 Participants – Work Settings

- School settings: 51% (994)
- Client homes: 24% (469)
- Private practice: 10% (115)
- [Other settings]
Primary Work Setting

- **School**: ASHA 53.00%, Survey 50.00%
- **College/University**: ASHA 2.00%, Survey 0.00%
- **Hospital**: ASHA 15.00%, Survey 12.00%
- **Skilled Nursing**: ASHA 2.00%, Survey 1.00%
- **Private Practice**: ASHA 5.00%, Survey 5.00%
- **Speech & Hearing Cntr**: ASHA 46.00%, Survey 47.00%
- **Client Homes**: ASHA 0.00%, Survey 0.00%
- **Early Head Start/Head Start Centers**: ASHA 2.00%, Survey 0.00%
2073 Participants – Primary Job Role

90%
(1,822)
Service providers
2073 Participants – Geographic Area

- Rural: 36.8% (728)
- Urban: 30.4% (601)
- Suburban: 48.9% (969)
PRELIMINARY FINDINGS

WHAT DO SLPS DO NOW?
WHAT SUPPORTS DO SLPS RECOMMEND?
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
Families ask for information about normal developmental milestones

I see a greater number of children who present with potential autism indicators

Families ask for information about developmental delays such as autism

The number of families who ask about autism has increased

When testing, I make referrals for children by 18 months of age if autism may be a concern or indicators are present

I have information to educate parents about monitoring their child’s communication, cognitive,…

When a child qualifies for speech-language services and autism may be a concern, I start intervention…

I discuss the need for further evaluation with families when autism may be a concern

When testing, I always look for potential indicators of developmental delays, including autism

When testing, I informally screen for autism

What SLPs do now

Strongly Agree N

Agree N

Disagree N

Strongly Disagree N

47.67% (870)
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. Easier to miss younger children-- indicators are not as obvious in young children.
Results consistent across variables & with NECTAC results.

There is support for validity of CSBS DP behavior sample in assessing early social communication skills that may help identify and distinguish children with ASD late in 2nd year of life.
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
- What can SLPs do to help referral sources
How prepared do you feel to do the following?

- Assess children with potential autism
- Communicate with families about autism
### SLPs felt least prepared to:

<table>
<thead>
<tr>
<th>Activity</th>
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<tbody>
<tr>
<td>Select and use screening tools for autism</td>
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<tr>
<td>Explain information about autism to families of differing cultures</td>
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<tr>
<td>Help families reach a diagnosis of autism (in general)</td>
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<tr>
<td>Discuss current evidence about autism with families</td>
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<tr>
<td>Access easy to read and appropriate resources about autism to share</td>
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# Information SLPs would like to have

<table>
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<tr>
<th>Top recommendations</th>
<th>%</th>
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<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>
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
- Journal articles
- Textbooks
- Colleagues/Specialists
- Professional meetings/conferences
- Pre-service/university graduate level training
How SLPs Acquire Information Now

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- Pre-service/university graduate level training

- NEVER
- OCCASIONALLY
- OFTEN
- ALWAYS
- N/A

- 66.24%
- 75.52%
- 68.54%
How SLPs acquire information now – key points

SLPs most often acquire information via websites, colleagues/specialists, and professional meetings/conferences

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

<table>
<thead>
<tr>
<th>Preference</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>1. Professional meetings/conferences</td>
<td>97.03%</td>
</tr>
<tr>
<td>2. Colleagues/Specialists</td>
<td>96.13%</td>
</tr>
<tr>
<td>3. CDC’s “Learn the Signs. Act Early.” campaign</td>
<td>94.74%</td>
</tr>
<tr>
<td>4. Hard copy products such as brochures, fact sheets</td>
<td>94.17%</td>
</tr>
<tr>
<td>5. Internet/Web</td>
<td>93.41%</td>
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How SLPs prefer to receive information, cont’d

<table>
<thead>
<tr>
<th></th>
<th>How SLPs prefer to receive information</th>
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<tr>
<td>6.</td>
<td>Emailed updates such as: enewsletters, listservs</td>
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<tr>
<td>7.</td>
<td>Journal articles</td>
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<tr>
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Re what takes place when autism is suspected:

- Some settings discourage screening for ASD; some not allowed to refer for further evaluation
- SLPs list a wide variety of tools used for screening
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)
• 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)
- Questions related to referral should have asked about referral sources to speech-language pathologists
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 - what SLPs do now, preparation level, and preferences vs knowledge and skills
- Questions adapted from ASHA, NECTAC, CDC, and Schwartz and Drager (2008), allow comparisons
- Findings can assist with future survey/interview questions
- 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?
Primary References


National Early Childhood Technical Assistance Center (NECTAC), Screening and Early Identification, Queries, updated report downloaded 11-09, http://www.nectac.org/~pdfs/pubs/queries/queries_asdscreening.pdf


Primary References, cont’d


