CDC/AUCD Collaborative Research Award

Involving Allied Health Care Professionals in Helping Parents Navigate Systems for ASD Diagnosis

LILY NALTY, MA, CCC-SLP

CENTER FOR DISABILITY RESOURCES, UNIVERSITY OF SOUTH CAROLINA, TEAM FOR EARLY CHILDHOOD SOLUTIONS - PART C TRAINING/TECHNICAL ASSISTANCE PROJECT
One of the first to come in contact with families (ASHA, 2006)

Early language and communication delays are first concerns of families (Wimpory, 2000)

Language, speech, and communication delays are most common (Hebbeler et al., 2007)

Early indicators of children with ASD diagnosis involve social communication and language (Wetherby, 2009)
Literature Review:
Developed endnote library - articles/documents within last 10 years
• Finding: Little related to what SLPs do now with young children (0-6 yrs) with potential ASD

Landscape audit:
Developed endnote library - current websites/products for families and providers
• Finding: Several partial repositories

Need: Learn what SLPs do now, what resources they recommend
Methods

National survey adapted for SLPs (2009) working with 0-6 year olds

- 2082 SLPs responded to the online survey
- 63% had 11+ years

Survey designed to determine resources for education & to use with families

- Current practices
- Level of preparation
- Practitioner recommendations
Survey results identified early identification practices of SLPs

- **73.6%** make referrals for children by 18 months of age if autism or indicators are present.
- **94.8%** have information to educate parents about monitoring their child’s communication, cognitive, social, and physical development.
- **94.1%** start intervention before a diagnosis is reached.
- **97.5%** always look for potential indicators of developmental delays, including autism.
- **95.7%** discuss the need for further evaluation with families when autism may be a concern.
- **81.7%** use published screeners designed to detect children who may be at-risk for autism.
- **45.3%** informally screen for autism.

*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, social, and physical development.*
*When a child qualifies for speech-language services and autism may be a concern, I start intervention before a diagnosis is reached.*
*When testing, I always look for potential indicators of developmental delays, including autism.*
*I discuss the need for further evaluation with families when autism may be a concern.*
*When testing, I use published screeners designed to detect children who may be at-risk for autism.*
*When testing, I informally screen for autism.*
Survey Results

Survey results identified SLPs’ self-reported readiness to carryout early identification practices

SLPs feel **MOST UNPREPARED** to:

- Discuss current evidence about autism with families: 41%
- Help families reach a diagnosis of autism: 42%
- Use screening tools to determine if a child may be at-risk for autism: 57%
- Explain information about autism to families of differing cultures: 61%
- Select screening tools for autism: 66%

SLPs feel **MOST PREPARED** to:

- Conduct speech-language evaluations with children who have autism or potential autism diagnosis: 77%
- Explain the role of Speech-Language Pathologists in early identification of autism: 83%
- Discuss a child's referral needs with families when autism may be a concern: 84%
- Explain speech-language indicators of autism with families: 86%
- Discuss normal developmental milestones with families: 97%
Resource and information recommendations varied

- **Least experienced SLPs** - resources on speech-language indicators of autism and overall methods for helping families reach earlier diagnosis
- **Based on practices used the least by least experienced SLPs** – resources on making referrals by 18 months of age, discussing referrals with families, and using published screeners
- **SLPs in rural areas** - information to share with families that is easy to read/understand

Referral issues

- SLPs feel prepared to discuss referral needs, but not with families of differing cultures
- Reported concerns include communication with referral sources for effective follow-up and knowing about or having evaluation sources
- SLPs most often refer to physicians and Part C early intervention systems and report infrequent referral to audiology and parent advocacy
  - Hearing evaluation is vital to differential diagnosis of ASDs
  - Parent advocacy providers can offer supports for families
Information and Resource Recommendations from the Survey

Practitioner resources and information related to early identification:
- Screening and screening tools, including early signs
- Referral sources and related strategies
- Communicating with families about autism, especially with families of differing cultures
- Having information that reflects current evidence in the field of autism
- Helping families reach an earlier diagnosis

Preferred formats for receiving information:
- Professional meetings
- Colleagues/specialists
- CDC’s “Learn the signs. Act early.” website
- Fact sheets and brochures
- Other professional websites

Practitioner resources and information related to communicating with families:
- Explain autism and current evidence about autism
- Discuss a child’s referral needs when autism may be a concern
- Help families reach a diagnosis

Material needs for sharing information with families:
- Easy to read and understand
- Adapted for families of differing cultures
- Adapted for families at varying levels of readiness
Outcomes

√ Comprehensive current literature review, annotated
√ Review of existing products and resources, with annotations
√ National and state level presentations
  • *CDC “Learn the Signs. Act Early.” SLP Expert Roundtable*, Round Table Session, American Speech-Language-Hearing Association (2009), Leaders: Katie Green, Wendy Ruben
  • *Communication and Language in Children with ASD*, An overview of what families and other team members should know about early indicators, ongoing challenges, & strategies to promote language in everyday activities, Webinar, S.C. Autism Society (2010), Presenters: Lily Nalty, Tim Conroy
  • *Critical Role of SLPs in Early Identification of ASDs and Supportive Resources*, session, S.C. Speech-Language-Hearing Association (February 2011), Presenters: Lily Nalty, Lesly Wilson
√ Manuscripts
  • *Critical Role in Earlier Diagnosis of Autism: Recommendations from Speech-Language Pathologists*, In Progress, ASHA Journal and others, Authors: Lily Nalty, Cheryl Rhodes, Martha Alexander, Georgina Peacock
Next Steps

√ Expand liaison with ASHA for such purposes as
  • co-sponsorship of webinar for continuing education credit
  • FAQ – issues raised by survey responses, comments, and presentation discussions

√ Continue and extend partnerships to the Physical Therapy Association (APTA) and the American Occupational Therapy Association (AOTA)
  • consult to implement PT and OT survey of practices and supports recommendations
  • disseminate findings and recommendations to allied health professionals through professional journals and presentations

√ Partner with other related groups such as
  • NECTAC and Act Early teams – to facilitate resources and information used by allied health professionals in early intervention systems and early childhood education programs

√ Compile all data to develop a comprehensive best practice resource to be posted on LTSAE website
PRIMARY REFERENCES


