Role of allied health professions in early detection of autism: National surveys of pre-referral practices and service implications

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Presenters

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- American Occupational Therapy Association (AOTA)
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- American Speech-Language-Hearing Association (ASHA)
- Association of University Centers on Disabilities (AUCD)
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“Learn the Signs. Act Early.”

Program

• 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.
Three Components

• Health education campaign
  ▪ materials and messages to promote awareness
• Act Early Initiative
  ▪ with state and national partners, improve early childhood systems
• Research and evaluation
  ▪ increase understanding of factors that influence early identification and referral
  ▪ improve campaign materials and implementation activities
Campaign Strategy

• To integrate Learn the Signs materials into national, state, and local programs that
  ▪ serve parents of young children
  ▪ serve populations with health disparities
  ▪ have interest or mandate in child development and screening
  ▪ common goal - to improve early identification
Background

• LTSAE/ASHA Collaboration
  ▪ ASHA-Campaign Partnership
  ▪ ASHA/Autism Expert Group

• AUCD Collaborative Research Award (2009)
  ▪ Involving Allied Health Care Professionals in Helping Parents to Navigate Systems for Autism Spectrum Disorder (ASD)
    ▪ Lily Nalty, MA, CCC-SLP, University of South Carolina, Center for Disability Resources
Current Collaboration

• CRA research findings expanded to include PTs and OTs
• PT and OT engagement in LTSAE campaign increased
• Collaborative activities
  ▪ Conference presentations
  ▪ Resource sharing
  ▪ Material review and development
Early Identification

CURRENT ROLE OF ALLIED HEALTH PROFESSIONALS
Autism Spectrum Disorders (ASDs)

- ASDs are a group of neurodevelopmental disabilities.
- May cause significant social, behavioral and communication challenges.
- CDC estimates that an average of 1 in 110 children in the U.S have an ASD\(^1\).

\(^1\)http://www.cdc.gov/ncbddd/autism/index.html
CDC Urgent Public Health Concern

• Increased concern in communities
• Increased demand for services
• Need for coordinated and serious response to improve lives of people with ASDs

1Autism and Developmental Disabilities Monitoring (ADDN) Network
http://www.cdc.gov/ncbddd/autism/addm.html
Age of Diagnosis

- Median age of diagnosis 4.5 to 5.5 years
- Research indicates autism diagnosis at early ages are reliable, valid, and stable
- One third of parents note signs before first birthday
- 80 percent of parents note concerns before 24 months

http://www.cdc.gov/ncbddd/autism/screening.html
Benefits of Early Diagnosis

- Estimated collective costs of ASD across the lifespan are $3.2 trillion
- Leads to better outcomes for children and increased support for families
  - Access to community services and resources including early intervention
- Impact continues throughout lifespan
Current Roles of Allied Healthcare Professionals

• Inter-disciplinary approach
• Multiple areas of expertise
• Emerging roles in early identification and intervention
• Further standards of care needed to guide allied healthcare professionals
SURVEY PURPOSE AND GOALS
Purpose

• Improve identification of young children with potential ASDs
• Identify strengths and gaps in early identification and referral practices
• Identify additional information supports
Goals

• Provide resource and referral information to families
• Identify current practices and level of preparation
• Develop resources and strategies to respond to practitioner recommendations
STUDY METHODS AND RESULTS

Learn the Signs. Act Early.
Methods

• Survey questions address early identification practices, relative strengths and needs, and recommendations for additional resources and information

• Convenience sample
  ▪ professional association membership

• About 4,000 therapists responded to one of three on-line surveys
  ▪ 3,812 surveys were analyzed
Survey Development

- **SLP**
  - Developed fall 2009
  - Completed fall 2010

- **PT**
  - Developed September 2010
  - Completed summer 2011

- **OT**
  - Developed winter 2010
  - Completed June 2011

Learn the Signs. Act Early.
Completed surveys

OT - 25% (1396)

PT - 9% (340)

SLP - 54% (2076)

Learn the Signs. Act Early.
### Respondents by Level of Experience

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<tr>
<th>Experience Level</th>
<th>Percentage</th>
<th>Range</th>
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<tbody>
<tr>
<td><strong>Most experienced</strong></td>
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<tr>
<td>11-20 yrs/21+ yrs</td>
<td>M = 67%</td>
<td>R = 63-75%</td>
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<td><strong>Middle experienced</strong></td>
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<tr>
<td>6-10 yrs</td>
<td>M = 16%</td>
<td>R = 12-19%</td>
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<td><strong>Least experienced</strong></td>
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<tr>
<td>1-5 yrs/student/fellow</td>
<td>M = 17%</td>
<td>R = 14-20%</td>
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Primary Roles

• Most respondents were service providers and clinicians
  ▪ 89-91% across disciplines
Current Practices: Most Often Used

• When testing, I always look for potential indicators of developmental delays, including autism
• I have information to educate parents about monitoring their child’s communication, cognitive, social, and physical development
• When a child qualifies for therapy services and autism may be a concern, I start intervention before a diagnosis is reached
Current Practices: Most often used

• I discuss the need for further evaluation with families when autism may be a concern
• For OT: Occupational Therapy Profiles (participation history) are useful in helping to identify some of the early signs of autism
• When testing, I informally screen for autism
I have information to educate parents about monitoring their child’s communication, cognitive, social, and physical development.

When a child qualifies for therapy 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.

Current Practices

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<th>SLP</th>
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Current Practices: Supports provided to families

• Coordinate with other agencies or professionals to help families obtain further evaluation
• Informational support, such as handouts, web links, etc.
• Incorporate a family perspective into an evaluation/assessment
• Ongoing contact with family and child to help monitor the child's progress and family's needs
Supports provided to help families navigate systems

- Informational support, such as handouts, web links, etc.: 81% SLP, 79% PT, 81% OT
- Coord. w/other agencies or professionals to help families obtain further evaluation: 80% SLP, 75% PT, 80% OT
- Ongoing contact w/family & child to help monitor the child's progress/family's needs: 74% SLP, 73% PT, 74% OT
- Incorporate a family perspective into an eval/assessment: 62% SLP, 62% PT, 68% OT

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Current Practices: Gaps and needed resources

- Current evidence in the field of autism
- Discipline-specific evaluation procedures when autism is a concern
- Screening and screening tools for autism
- Role of therapist in early identification of autism
Current Practices: Gaps and needed resources

Information for families about autism that is easy to read and understand

Methods for explaining information about autism to families of differing cultures
Screening tools most often used

Ages and Stages (ASQ or ASQ SE)
- SLP: 21%
- PT: 19%
- OT: 31%

Modified Checklist for Autism in Toddlers (M-CHAT)
- SLP: 15%
- PT: 14%
- OT: 16%

Autism Behavior Checklist (ABC)
- SLP: 19%
- PT: 8%
- OT: 10%
Current Referral Practices

• Developmental pediatrician  58%
• Part C early intervention   45%
• Family pediatrician/physician  43%
Referral Practices

- Developmental pediatrician: 52% SLP, 51% PT, 45% OT, 72% total
- Part C: 42% SLP, 43% PT, 50% OT, 70% total
- Family pediatrician/physician: 42% SLP, 43% PT, 45% OT, 70% total

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Preferred Methods to access resources

1. Professional meetings/conferences
2. Colleagues/specialists
3. Internet/Web
4. LTSAE Campaign
5. Hard copy products (brochures, fact sheets)
6. Emailed updates (listservs or enewsletters)
For professionals and Families

RESOURCES BY FINDINGS & RECOMMENDATIONS
Resource Links

• Autism Speaks www.autismspeaks.org
  – Resources for families including *Autism 101*

• First Signs www.firstsigns.org
  – ASD video library; screening, information for families

• NECTAC www.nectac.org
  – Current info for practitioners

• Medline Plus.gov www.medlineplus.gov
  – Local resources, translations
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APTA http://www.pediatricappta.org/
Learn the Signs. Act Early.
• APTA Learning Center
  • Pediatrics: A Primer for Physical Therapists on Autism Spectrum Disorders (ASD) - Part I and Part II
  • On-line CEU course
• Role of the Physical Therapy in Autism  
  fact sheet in progress
• Section on Pediatrics Annual Conference
  • August 31 - September 2, 2011, Disneyland Hotel, Anaheim, CA
  • www.SoPAC.us
• Section on Pediatrics Partner's Program
  • http://www.pediatricapta.org/partners.cfm
• Legislative Issue Brief  
  fact sheet in progress
ASHA Autism Information

**ASHA Autism Resources**
- General Information
- Autism Causes & Numbers
- Benefits of Speech-Language Pathology Services
- ASHA Products
- Books on Autism and Aspergers
- Treatment Efficacy Summary on Autism

**ASHA Practice Policy Documents Related to Autism**
- Roles and Responsibilities of Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span [Position Statement]
- Knowledge and Skills Needed by Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span
- Guidelines for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span

**What other organizations have information about autism?**
- Autism Society of America
- Autism Speaks
- Watch video clips of early red flags of autism

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**Autism (Autism Spectrum Disorders)**

See Also:
- Autism: Causes and Number
- Autism: Benefits of Speech-Language Pathology Services

**What is autism?**

Autism is a developmental disability that causes problems with social skills and communication. Autism can be mild or severe. It is different for every person. Autism is also known as autism spectrum disorders.

**What are some signs or symptoms of autism?**

Children with autism may have problems with communication, social skills, and reacting to the world around them. Not all behaviors will exist in every child. A diagnosis should be made by the child's doctor or other professional with experience in working with children with autism. Possible signs and symptoms are outlined below.

**Communication:**
- Not speaking or very limited speech
- Loss of words the child was previously able to say
- Difficulty expressing basic wants and needs
- Poor vocabulary development
- Problems following directions or finding objects that are named
- Repeating what is said (echolalia)
- Problems answering questions
- Speech that sounds different (e.g., "robotic" speech or speech that is high-pitched)

**Social skills:**
- Poor eye contact with people or objects
- Poor play skills (pretend or social play)
- Being overly focused on a topic or objects that interest them
- Problems making friends
- Crying, becoming angry, giggling, or laughing for no known reason or at the wrong time
- Disliking being touched or held

**Reacting to the world around them:**
- Rocking, hand flapping or other movements (self-stimulating movements)
- Not paying attention to things the child sees or hears
- Problems dealing with changes in routine
- Using objects in unusual ways
- Unusual attachments to objects
- No fear of real dangers
FREE Resources
Health Professionals
Parents
Early Educators
Outreach
www.cdc.gov/actearly
click on “Free Materials”

www.cdc.gov/autism
AOTA microsite on Autism

http://aota.org/Practitioners/PracticeAreas/Pediatrics/Browse/Autism.aspx

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AOTA Autism Resources

- AOTA FAQ on Autism (member only)

- AOTA Practice Guidelines for Children and Adolescents with Autism

- AOTA evidence based review: interventions on autism used in or relevance for OT
  http://www1.aota.org/ajot/abstract.asp?IVol=62&INum=4&ArtID=6&Date=July/August%202008

- Tips for Educators on OT Role with Students with Autism

- AOTA Fact Sheet on Autism
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AOTA Specialty Conference

2011 Specialty Conference - Autism West

AOTA SPECIALTY CONFERENCE
Autism West

December 2-3, 2011 • Long Beach, California

http://www.aota.org/ConfandEvents/Autism-West.aspx
STRENGTHS AND LIMITATIONS OF THE SURVEY
Strengths

- Inter-disciplinary approach
- Large number of respondents
- Greater access: web based methodology
- See similar trends—themes threads cross disciplines—greater validity
- Instructional opportunity
Strengths

• Allowed for targeted support and resource dissemination
• Findings are representative of professionals affiliated with their respective associations
Limitations

• Need to interpret the findings given the methods that were used
  ▪ Self-identified sample
  ▪ Sample may be biased
  ▪ More members responding
  ▪ More technology savvy
  ▪ Not calculated response rate
Reflections

BENEFITS AND IMPLICATIONS
Benefits of the Project

• Promotion and prevention emphasis
• Full scope of practice promoted
• Better potential outcomes for children and families
• Stronger alliances
• Implications for educational programming and resource development
Benefits of the Partnership

• Learning from each other across disciplines
• Similarities and differences identified
• Developing future steps/plans
• Stronger, unified messages
• Collected efforts improve opportunity to influence policy and practice
• Translation from policies to practices
• Different levels of scale
Implications

- Allied Health Professionals continue to support families in early identification of autism and other developmental disabilities
- As a result of this research we have a better understanding of referral practices
- Stronger partnership - plans and activities
Next steps

• Federal: CDC training modules
• National: information dissemination through professional associations
  ▪ Conferences, networks, newsletter
• State: Illinois LEND as model
Screening module
• Continuation of CDC-Allied Health Partnership
  ▪ Beginning of a roadmap for future directions
  ▪ FAQs
Questions? Comments?

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