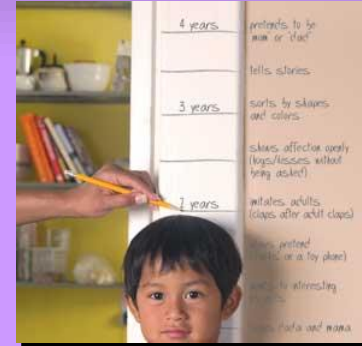


# Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities



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

AUCD Conference  
Washington DC  
November 8, 2011

Learn the Signs. Act Early.

# Presenters

- **Elisa Kennedy, PT PhD PCS**  
University of Alabama, Chair, APTA Early Intervention Division and Autism SIG
- **Lily Nalty MA, CCC-SLP**  
Center for Disability Resources, University of South Carolina SOM
- **Cheryl Rhodes, MS LMFT**  
CDC/NCBDDD, AUCD Fellow
- **Sandra Schefkind, MS, OTR/L,**  
American Occupational Therapy Association,  
Pediatric Coordinator

Learn the Signs. Act Early.

# Acknowledgements

Organizational support of this research:

- American Occupational Therapy Association (AOTA)
- American Physical Therapy Association (APTA)
- American Speech-Language-Hearing Association (ASHA)
- Association of University Centers on Disabilities (AUCD)

# Contributors

- Kris Pizur-Barnekow, PhD, OTR/L Associate Professor, University of Wisconsin-Milwaukee
- Lesly Wilson, PhD, OTR/L, Research Assistant Professor, Center for Disability Resources, University of SC SOM, Pediatrics
- University of South Carolina CDR, TECS Data and Training Specialists
  - Renee Sewell
  - Lisa Henry

# Contributors

- Kathy Stemm, DSc, PT, PCS Chair, Autism Task Force APTA
- University of South Alabama, PT Student Investigators
  - Katelyn Caraway
  - Jennifer Melancon
  - Rebecca Oliver

# **“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

**Learn the Signs. Act Early.**

# 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**

**Learn the Signs. Act Early.**

# 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<sup>1</sup>.

<sup>1</sup><http://www.cdc.gov/ncbddd/autism/index.html>

**Learn the Signs. Act Early.**

# 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<sup>1</sup>

<sup>1</sup>Autism and Developmental Disabilities Monitoring (ADDM) Network  
<http://www.cdc.gov/ncbddd/autism/addm.html>

**Learn the Signs. Act Early.**

# 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>

**Learn the Signs. Act Early.**

# 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

**Learn the Signs. Act Early.**



# **SURVEY PURPOSE AND GOALS**

**Learn the Signs. Act Early.**

# 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

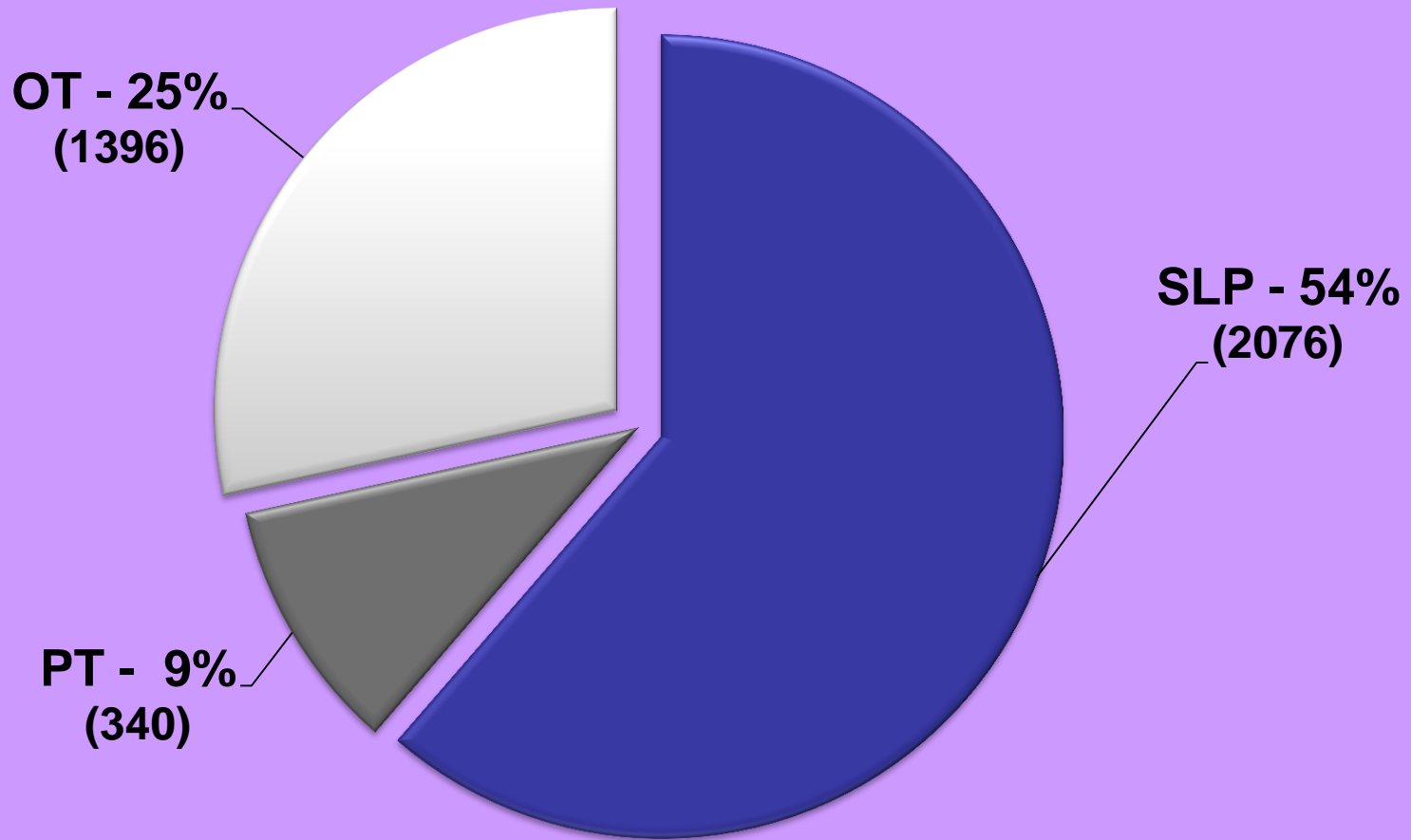
- Developed September 2010
- Completed summer 2011

OT

- Developed winter 2010
- Completed June 2011

Learn the Signs. Act Early.

# Completed surveys



Learn the Signs. Act Early.

# Respondents by Level of Experience

<b>Most experienced</b> •11-20 yrs/21+ years	<b>M = 67%</b>	<b>R = 63-75%</b>
<b>Middle experienced</b> •6-10 yrs	<b>M = 16%</b>	<b>R = 12-19%</b>
<b>Least experienced</b> •1-5 yrs/student/fellow	<b>M = 17%</b>	<b>R = 14-20%</b>

Learn the Signs. Act Early.



# Primary Roles

- Most respondents were service providers and clinicians
  - 89-91% across disciplines

# Current Practices: Most Often Used

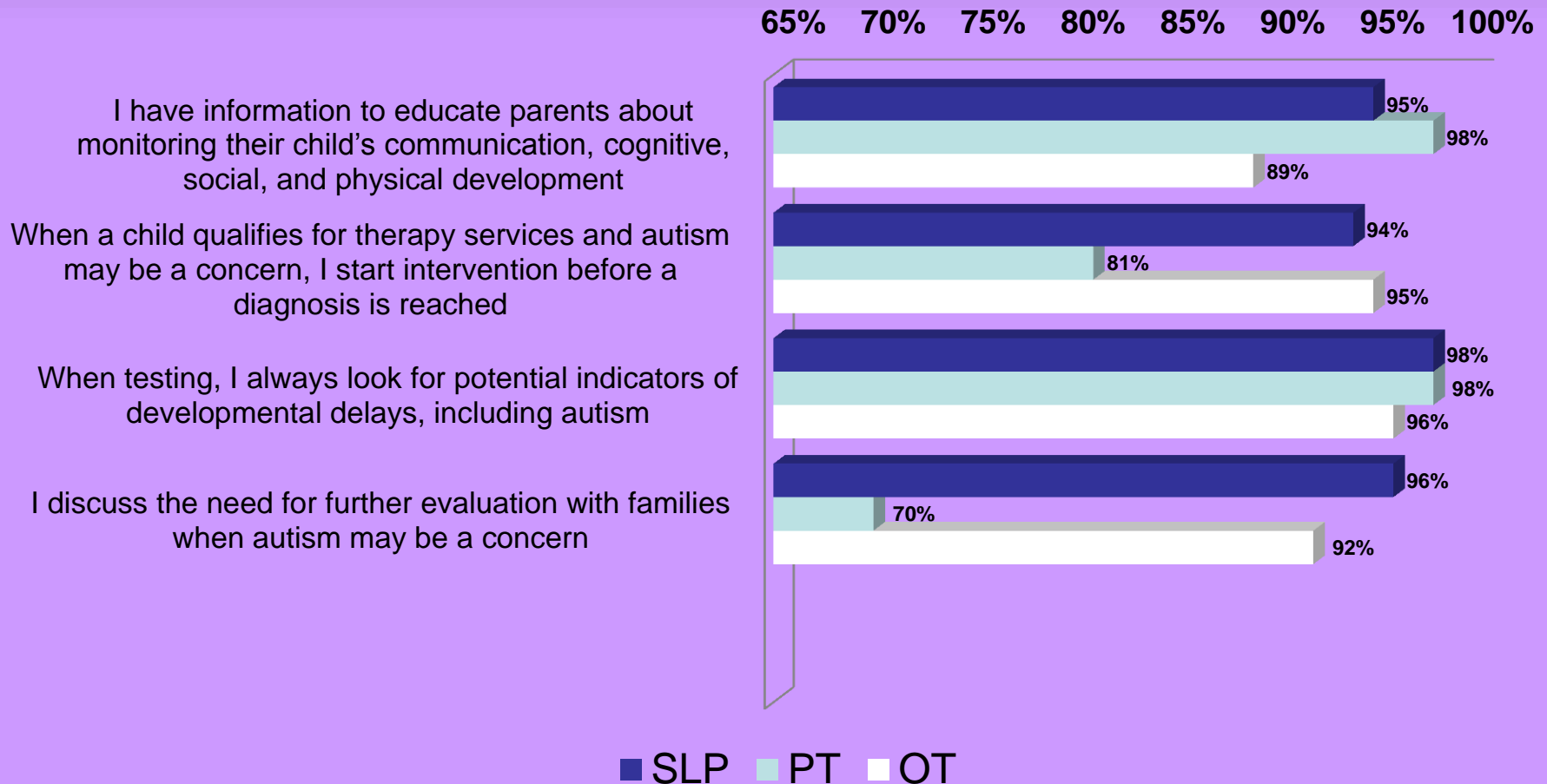
- When testing, I always look for potential indicators of developmental delays, including autism
- I have information to educate parents about monitoring their child's communication, cognitive, social, and physical development
- When a child qualifies for therapy services and autism may be a concern,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

**Learn the Signs. Act Early.**

# 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

# Current Practices

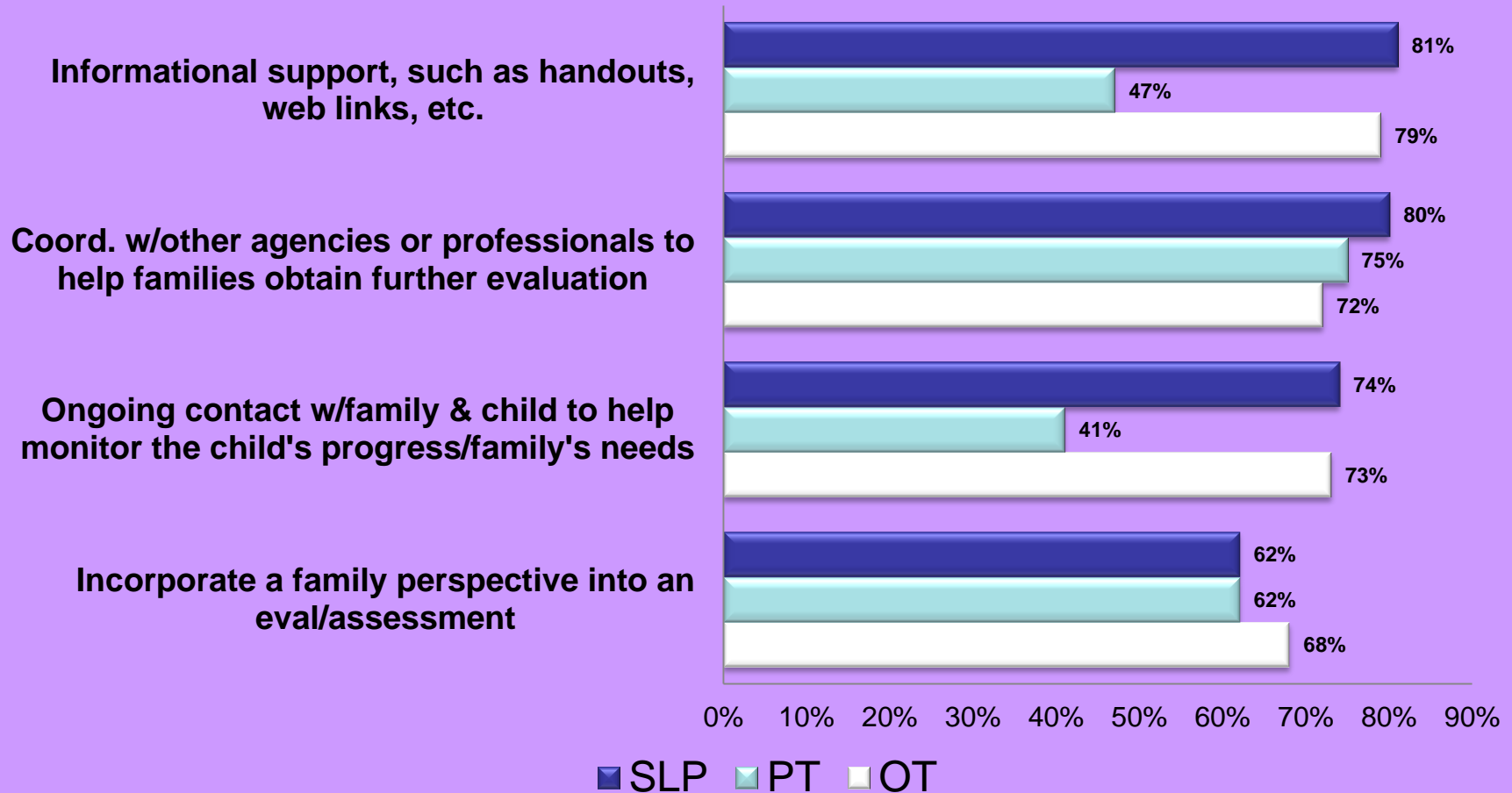


**Learn the Signs. Act Early.**

# 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



**Learn the Signs. Act Early.**

# 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



**Learn the Signs. Act Early.**

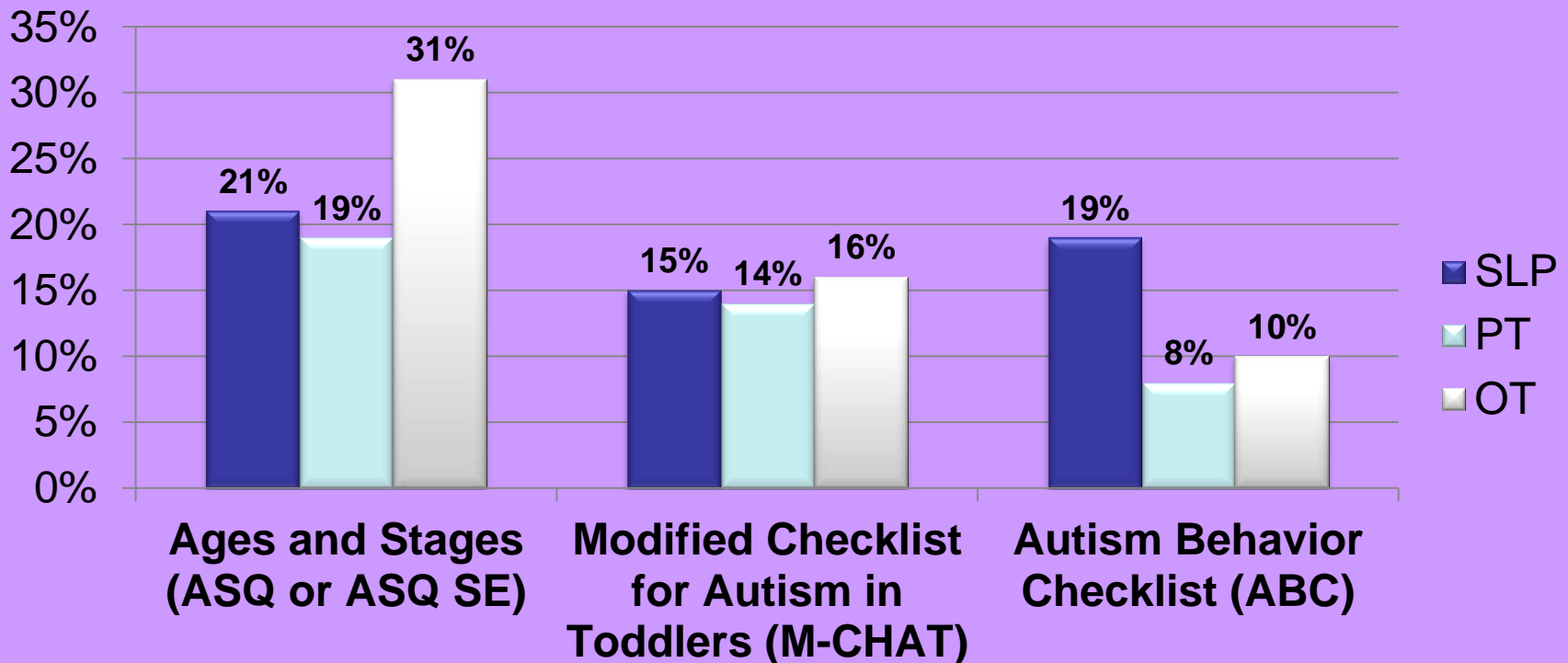
# Current Practices: Gaps and needed resources

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

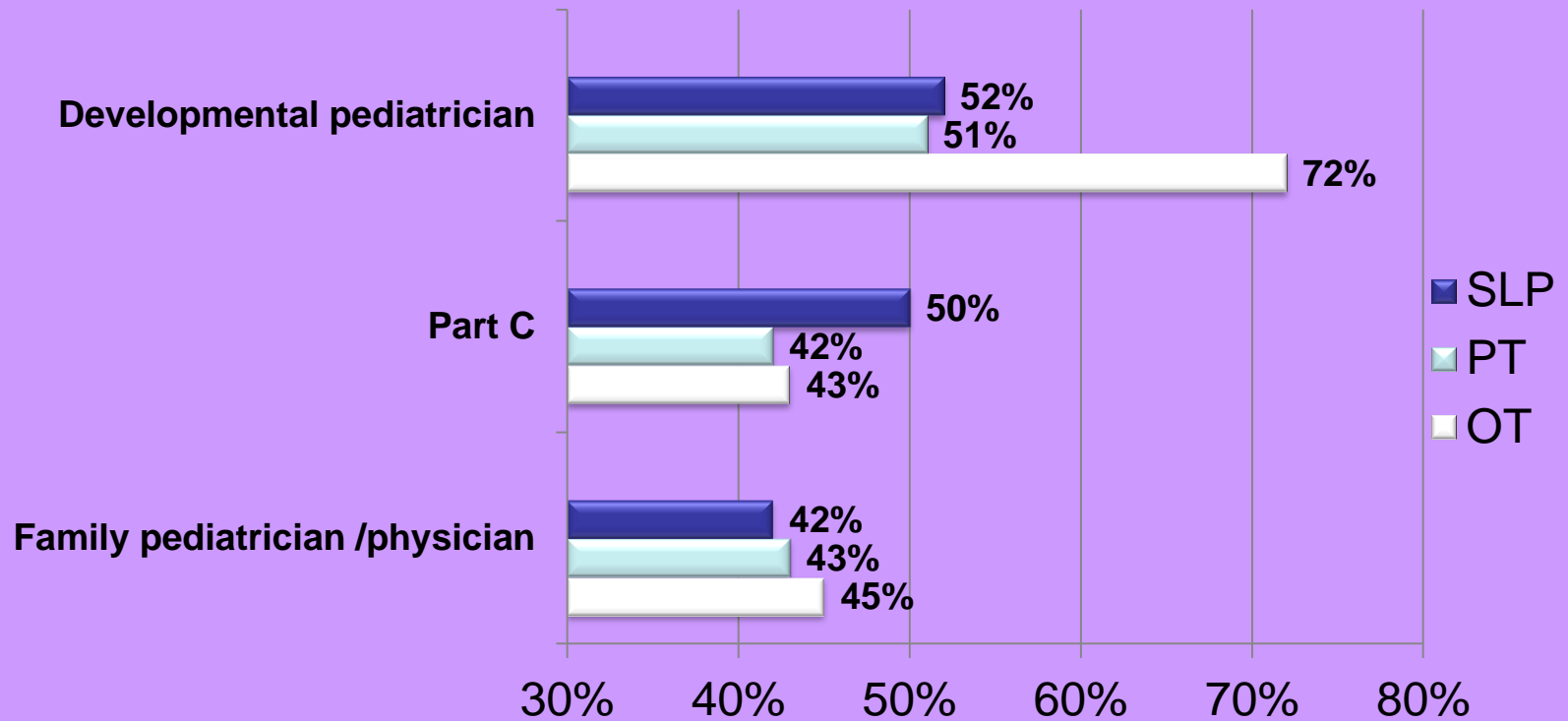


Learn the Signs. Act Early.

# Current Referral Practices

- Developmental pediatrician 58%
- Part C early intervention 45%
- Family pediatrician/physician 43%

# Referral Practices



**Learn the Signs. Act Early.**

# 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 newsletters)

Learn the Signs. Act Early.

For professionals and Families

# **RESOURCES BY FINDINGS & RECOMMENDATIONS**

Learn the Signs. Act Early.

# Resource Links

- Autism Speaks [www.autismspeaks.org](http://www.autismspeaks.org)
  - Resources for families including *Autism 101*
- First Signs [www.firstsigns.org](http://www.firstsigns.org)
  - ASD video library; screening, information for families
- NECTAC [www.nectac.org](http://www.nectac.org)
  - Current info for practitioners
- Medline Plus.gov [www.medlineplus.gov](http://www.medlineplus.gov)
  - Local resources, translations

# APTA <http://www.pediatricapta.org/>

Consumer Resource Links- Section on Pediatrics - APTA - Mozilla Firefox

File Edit View History Bookmarks Tools Help

Consumer Resource Links- Section o...

pediatricapta.org https://www.pediatricapta.org/consumer-patient-information/resources.cfm

Most Visited Getting Started Latest Headlines

home  
about the section  
healthcare professionals  
healthcare consumers  
research & awards  
special interest groups  
regional news  
contact us  
join us!  
logout

1111 N. Fairfax St., Alexandria, VA 22314  
(800)999-2782 x3254 pediatric@apta.org

Search PediatricAPTA Site

A Component of the American Physical Therapy Association

Consumer Resource Center

**Section on Pediatrics Fact Sheets for Consumers**

- Promoting Your Child's Development: Information Resources for Families of Children with Disabilities
- Resources on Fitness for Young Children
- ABCs of Pediatric PT
- ABCs of Pediatric Physical Therapy Slide Show
- Early Intervention: Physical Therapy Under IDEA
- Providing Physical Therapy in the School Systems Under IDEA
- Promoting Social Emotional Development: An Introduction for Families and Caregivers
- El ABC de la fisioterapia pediátrica  
*The ABCs of Pediatric Physical Therapy*
- Intervención temprana: fisioterapia según la IDEA  
*Early Intervention: Physical Therapy Under IDEA*
- Promoción del desarrollo de su hijo: información recursos para familias de niños con discapacidades  
*Promoting Your Child's Development: Information Resources for Families of Children with Disabilities*
- Provisión de fisioterapia en las escuelas según la IDEA 2004  
*Providing Physical Therapy in the School Systems Under IDEA*
- Promoción del desarrollo socio-emocional: una introducción para las familias y los cuidadores  
*Promoting Social Emotional Development: An Introduction for Families and Caregivers 2009*

Learn the Signs. Act Early.

# APTA member only

**Section on Pediatrics Fact Sheets - Section on Pediatrics - APTA - Mozilla Firefox**

File Edit View History Bookmarks Tools Help

Section on Pediatrics Fact Sheets- S... +

pediatricapta.org https://www.pediatricapta.org/members/member-fact-sheets.cfm

Most Visited Getting Started Latest Headlines

Search Pediatric/APTA Site

**Section on Pediatrics Fact Sheets**

**Information for Physical Therapists and Other Service Providers**

**General**

- Foundations of Pediatric Orthotics
- Using APTA's Guide to Physical Therapist Practice in Pediatric Settings
- A Pediatric Case Example: Application of the Guide to Physical Therapist Practice
- Evidence-based Practice in Pediatric Physical Therapy
- Team-based Service Delivery Approaches in Pediatric Practice

**Reimbursement**

- Resources for Reimbursement for Pediatric Physical Therapy Services and Durable Medical Equipment
- What Providers of Pediatric Physical Therapy Services Should Know About Medicaid

**Intervention**

- Considering Interventions from Alternative & Complementary Medicine
- Intervention for Youth Who Are in Transition from School to Adult Life
- Using Evidence to Select an Ankle Foot Orthosis (AFO) for Children with Cerebral Palsy

**Other**

- Assistive Technology Resources
- Body-Weight-Supported Treadmill Training: Using Evidence to Guide Physical Therapy Intervention
- Developmental Coordination Disorder
- Assistive Technology and the Individualized Education Program
- Deformational Plagiocephaly & Cranial Remolding in Infants
- Natural Environments in Early Intervention Services

[Click here](#) for Information for Families and Spanish-language Resources

**our community JOIN**

**PEDS Stuff** online store

**CAREER CENTER** SEARCH • POST

**CSM 2012** chicago

**IDEA Manual** UPDATED order here

**SECTION ON PEDIATRICS**

© copyright. All rights reserved. pediatricapta.org

home about us professionals consumers research news & events SIGs regions contact

Learn the Signs. Act Early.



# APTA Additional Resources

- 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](http://www.SoPAC.us)
- Section on Pediatrics Partner's Program
  - <http://www.pediatricapta.org/partners.cfm>
- Legislative Issue Brief *fact sheet in progress*

Learn the Signs. Act Early.



AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION  
Making effective communication, a human right, accessible and achievable for all.

CAREERS | CERTIFICATION | PUBLICATIONS | EVENTS | ADVOCACY | CONTINUING EDUCATION | PRACTICE MANAGEMENT | RESOURCES

Home > About ASHA > Press Room

## ASHA Autism Information

### ASHA resources, actions, and information about autism

Press Release: ASHA Says Evidence-Based Approach Should Guide National Autism "Conversation"

Evidence-Based Practice: A Guide For The Autism Conversation

Letter to Senator McCain [PDF]

Letter to Senator Obama [PDF]

Study: No link between measles vaccine and autism

**Podcast**  
ASHA fellow and speech-language pathologist, Amy Wetherby, discusses the importance of early autism detection .

**The ASHA Leader Articles**

- Language Outcomes for Young Children with Autism Spectrum Disorders
- A Unique Mind: Learning Style Differences in Asperger's Syndrome and High-Functioning Autism
- Closing the Gap in Treatment of Severe Disabilities and Autism
- New Autism Collaboration Develops Practices in Communication Assessment for SLPs

**What other organizations have information about autism?**  
This list is not exhaustive and inclusion does not imply endorsement of the organization or the content of the Web site by ASHA.

- Autism Society of America
- Autism Speaks

Watch video clips of early red flags of autism

**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 [PDF]

**ASHA Practice Policy Documents Related to Autism**

- Principles for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span [Technical Report]
- 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 for 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

## Autism (Autism Spectrum Disorders)

- What is autism?
- What are some signs or symptoms of autism?
- How is autism diagnosed?
- What treatments are available for people with autism?
- What other organizations have information about autism?

### 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

Learn the Signs. Act Early.

## FREE Resources

Health Professionals  
Parents  
Early Educators  
Outreach

[www.cdc.gov/actearly](http://www.cdc.gov/actearly)

click on “Free Materials”

[www.cdc.gov/autism](http://www.cdc.gov/autism)

CDC Home  
**CDC** Centers for Disease Control and Prevention  
Your Online Source for Credible Health Information

A-Z Index [A](#) [B](#) [C](#) [D](#) [E](#) [F](#) [G](#) [H](#) [I](#) [J](#) [K](#) [L](#) [M](#) [N](#) [O](#) [P](#) [Q](#) [R](#) [S](#) [T](#) [U](#) [V](#) [W](#) [X](#) [Y](#) [Z](#) <#>

### Learn the Signs. Act Early.

[National Center Homepage](#) > [Learn the Signs Home](#)

#### Free Materials



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](#)

**Learn the Signs Home**

- Milestones
- If You're Concerned
- Facts
- Free Materials**
- Download Materials
- Video, E-Cards, PSAs
- Links to Other Websites
- About the Campaign

**Information For...**

- Parents
- Healthcare Providers
- Early Childhood Educators
- Partners
- Media
- Policy Makers

**Learn the Signs. Act Early.**

# AOTA

## AOTA microsite on Autism

**AOTA** The American Occupational Therapy Association, Inc.

Living Life To Its Fullest™

Practitioners | Educators-Researchers | Students | About Occupational Therapy | OT Connections

Home > Practitioners > Practice Areas > Children and Youth > Browse > Autism Resources

### Autism Resources

Welcome to our Autism micro-site. With so many practitioners working with persons with autism, AOTA has developed extensive resources on this topic, and this page organizes all of these resources in one area. Whether you're looking for news, Conference sessions, AJOT articles, books, research, or other tools, you can find it all here.

- [News](#)
- [Practice](#)
- [Continuing Education](#)
- [OT Practice Articles](#)
- [AJOT Articles](#)
- [SIS Quarterly Articles](#)
- [Books](#)
- [OT Connections Networking](#)
- [Media](#)
- [Consumer Information](#)
- [Research](#)
- [Policy Information](#)
- [Autism Organizations](#)
- [Other Resources](#)

### News

- [The Interagency Autism Coordinating Committee \(IACC\) and the Office of Autism Research Coordination \(OARC\) are pleased to announce the release of the 2010 IACC Strategic Plan for Autism Spectrum Disorder Research.](#)
- [Major Databases Link Up to Advance Autism Research](#)
- [Autism Intervention for Toddlers Improves Developmental Outcomes](#)

[back to top](#)

### Practice

### Information

- [Autism Fact Sheet](#)
- [Autism FAQ \*\*NEW!\*\*](#)
- [Occupational Therapy and School Mental Health Fact Sheet](#)
- [Health Insurance Coverage for Individuals With Autism](#)
- [OT Practice Guideline for Children and Youth with Autism](#)
- [OT Practice Guideline for Children with Behavioral and Psychosocial Needs](#)

**OT Practice is ONLINE NOW!**  
[www.otpractice.org/currentissue](http://www.otpractice.org/currentissue)

**Join AOTA Now!**

**CE** CE 1.00  
Evidence-Based Review of Interventions Used in Occupational Therapy for Children With Autism Spectrum Disorder  
Presented by  
Janet Carr-Saunders, PhD, OTR/L, FAOTA, BCOT, BCSP  
AOTA  
CE CD

**SENSORY INTEGRATION**

**Occupational Therapy Practice Guidelines for Children and Adolescents With Autism**

The American Occupational Therapy Association, Inc.

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

Learn the Signs. Act Early.

# AOTA Autism Resources

- **AOTA FAQ on Autism (member only)**  
<http://www.aota.org/practitioners/practiceareas/pediatrics/browse/MH/autism.aspx?FT=.pdf>
- **AOTA Practice Guidelines for Children and Adolescents with Autism**  
[http://myaota.aota.org/shop\\_aota/prodview.aspx?TYPE=D&PID=843&SKU=2212](http://myaota.aota.org/shop_aota/prodview.aspx?TYPE=D&PID=843&SKU=2212)
- **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**  
<http://www.aota.org/practitioners/practiceareas/pediatrics/browse/MH/tip-sheet.aspx?FT=.pdf>
- **AOTA Fact Sheet on Autism**  
<http://aota.org/Consumers/Professionals/WhatIsOT/CY/Fact-Sheets/38517.aspx?FT=.pdf>

**Learn the Signs. Act Early.**

# AOTA Specialty Conference



December 2-3, 2011 \* Long Beach, CA

<http://www.aota.org/ConfandEvents/Autism-West.aspx>

**Learn the Signs. Act Early.**



# STRENGTHS AND LIMITATIONS OF THE SURVEY

Learn the Signs. Act Early.

# 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**

**Learn the Signs. Act Early.**

# 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?

- Presenter contact information:
  - Elisa Kennedy      [ekennedy@usouthal.edu](mailto:ekennedy@usouthal.edu)
  - Lily Nalty          [lily.nalty@uscmed.sc.edu](mailto:lily.nalty@uscmed.sc.edu)
  - Cheryl Rhodes      [crhodes1@cdc.gov](mailto:crhodes1@cdc.gov)
  - Sandy Schefkind    [sschefkind@aota.org](mailto:sschefkind@aota.org)

Learn the Signs. Act Early.