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

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Center for Disability Resources

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

(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;

- 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)

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

http://www.cdc.gov/ncbddd/actearly/freematerials.html

Google

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☆ 🧩 CDC CDC - Educational Materials Learn the Signs. Act Early...

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

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

FIRST WORDS®
PROJECT

What Is FIRST WORDS PROJECT?

Early Identification of Communication Delays

Autism Spectrum Disorders

Research

For Parents

For Healthcare and Childcare Providers

Related Websites

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.

Developmental Delays - Developmental Disabilities - Autism - Screening - Diagnosis - Early Intervention - First Signs

First Signs®

Identify early warning signs with First Signs products. FIND OUT MORE

ASD Video Glossary | In Your State | Research | Resources | Products

Who We Are

Concerns About A Child

Screening

Diagnosis & Treatment

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

What's new and worth knowing about...

Just released: *The First Year®: Autism Spectrum Disorders: An Essential Guide for the Newly Diagnosed Child*, by founder and president, Nancy D. Wiseman (Da Capo Press, 2009). [Read more information and reviews | Read an excerpt | Read the Table of Contents | Order online]

Special offer now through January 2010. Order a *First Signs Screening Kit*, receive a 25% discount, and a complimentary copy of the book, *The First Year: Autism Spectrum Disorders: An Essential Guide for the Newly Diagnosed Child.* [Get more

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Autism Resources 🔵 ASHA Members

... 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
http://www.asha.org/about/news/2009/AutismResources.htm - 27 KB
Cached | Details

📄 **Autism Spectrum Disorders Assessment**

Early Identification of ASD in Young Children

Printer-friendly Pag

- Contact Lists and Finder
- Topic Pages
- Conferences and Calendars
- Projects Finder
- Publications
- eNotes

A Training Model for the Diagnosis of Autism in Community Pediatric Practice, by Zachary Warren and Wendy Stone, was published in the October 2009 issue of the *Journal of Developmental & Behavioral Pediatrics*.

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.

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autism   Search MedlinePlus   Search Help

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Other Resources (23)
Multiple Languages (4)

Autism

Autism is a disorder that is usually first diagnosed in early childhood. The main signs and symptoms of autism involve communication, social interactions and repetitive behaviors.

Children with autism might have problems talking with you, or they might not look you in the eye when you talk to them. They may have to line up their pencils before they can pay attention, or they may say the same sentence again and again to calm themselves down. They may flap their arms to tell you they are happy, or they might hurt themselves to tell you they are not. Some people with autism never learn how to talk. (Read more)

Results 1 - 10 of 316 for autism

Clusters

All Results (316)   remix
+ Genetics (34)
+ Mental Health (25)

1. **Autism** (National Library of Medicine)
   Autism is a disorder that is usually first diagnosed in early childhood. The main signs and symptoms of autism involve communication, social interactions and repetitive behaviors. Children ...
   www.nlm.nih.gov/medlineplus/autism.html - Health Topics

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Medical Encyclopedia (13)
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Multiple Languages (4)

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clusters for this search.

Results 1 - 4 of 4 for autism

1. **Autism** – Multiple Languages: MedlinePlus
   Autism – Multiple Languages Russian (Русский) Somali (af Soomaali) Spanish (español) Russian (Русский) **Autism** – English Аутизм – Русский (Russian) Multimedia Healthy Roads Media ...
   www.nlm.nih.gov/medlineplus/languages/autism.html - Multiple Languages

2. Health Information in Somali (af Soomaali): MedlinePlus
   ... af Soomaali (Somali) PDF Bilingual Health Information Translations **Autism** **Autism** – English Xaalad **Autism**-ka – af Soomaali (Somali) Multimedia Healthy Roads Media ...
   www.nlm.nih.gov/medlineplus/languages/somali.html - Multiple Languages

3. Health Information in Russian (Русский): MedlinePlus
   ... предсердий – Русский (Russian) PDF Bilingual Health Information Translations **Autism** **Autism** – English Аутизм – Русский (Russian) Multimedia Healthy Roads Media ...
   www.nlm.nih.gov/medlineplus/languages/russian.html - Multiple Languages

4. Health Information in Multiple Languages – All Health Topics: MedlinePlus
   ... American Health Asthma Asthma in Children Atrial Fibrillation **Autism** B Return to top Back Injuries Back Pain ...
   www.nlm.nih.gov/medlineplus/languages/all_healthtopics.html - Multiple Languages

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A service of the National Library of Medicine and the National Institutes of Health

Your source for health services in your community.

http://www.handsonhealth-sc.org/golocal/golocalTOC.php?nid=153&county_id=46   Yahoo! Search

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Autism Services for York County: Go Local-SC

Page · Tools

go Local south carolina
An online guide to local health resources

Search Go Local Resources:
Enter a topic here   Go

Hands on Health-SC » Go Local » Autism » York County » Autism Services for York County

Autism Services for York County

Resources in York County (24)

Adult Day Care Services (5)   Counselors/Therapists (3)   Psychiatrists (3)
Clinical Social Workers (3)   Group Homes (1)   Psychologists (3)
Community Clinics (3)   Mental Health Clinics/Programs (3)

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HOH-SC Home

Regional resources also serving York County (12)

Advocacy Services (2)   Referral Services (1)   Support Groups (2)
Disability Programs (2)   Respite Care Services (3)
Home Health Care Services (1) Speech Therapists (1)

Resources serving all of South Carolina (63)

This state icon indicates services that are provided

Advocacy Services (6)   Genetic Counselors (1)   Pediatricians (4)

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

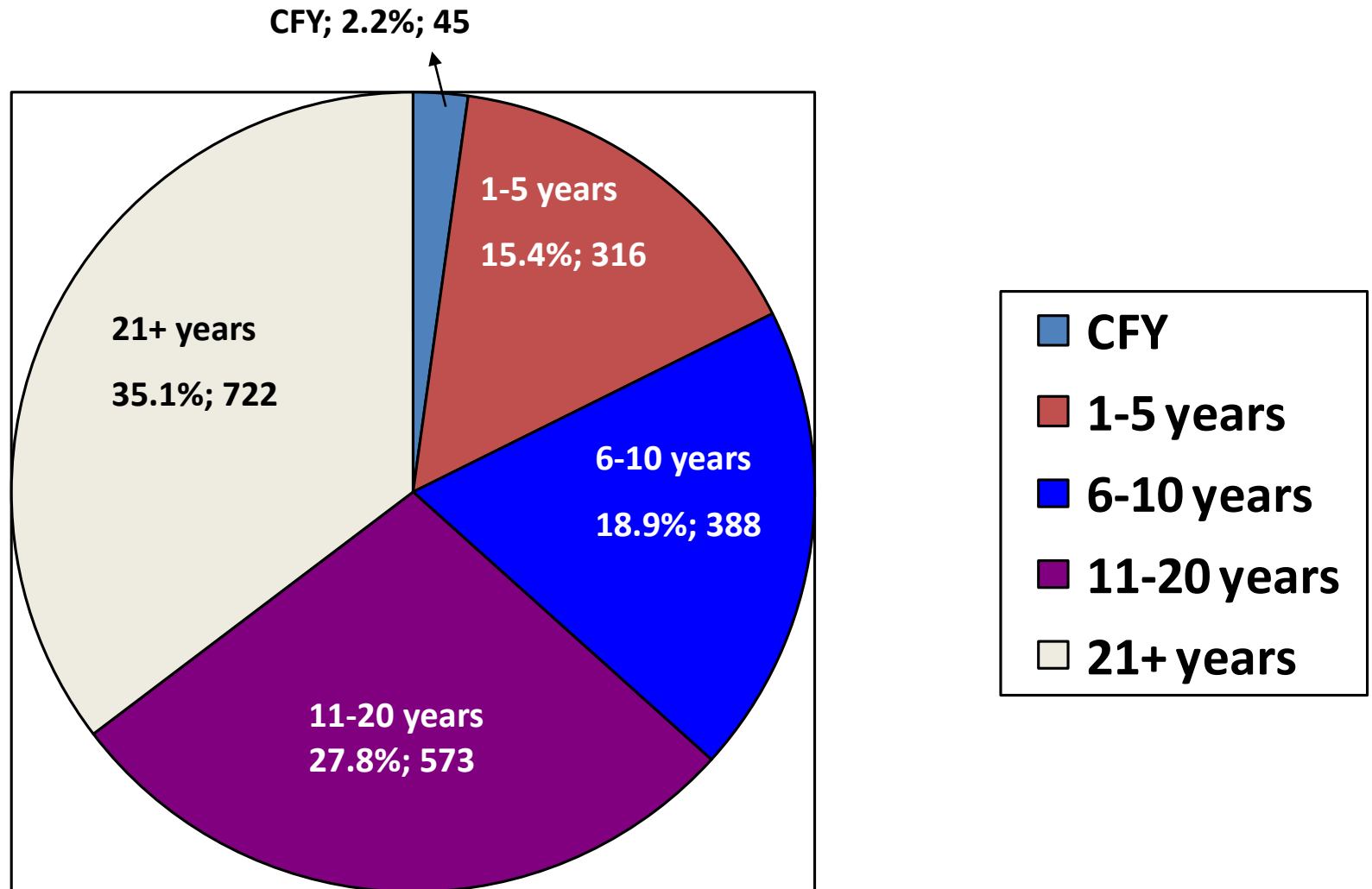- Analyze results from 2073 respondents (convenience sample)

PRELIMINARY FINDINGS

WHO PARTICIPATED?

2073 Participants – Yrs of Experience

CFY; 2.2%; 45

1-5 years
15.4%; 316

6-10 years
18.9%; 388

11-20 years
27.8%; 573

21+ years
35.1%; 722

Legend:
- CFY
- 1-5 years
- 6-10 years
- 11-20 years
- 21+ years

Age (25-54)
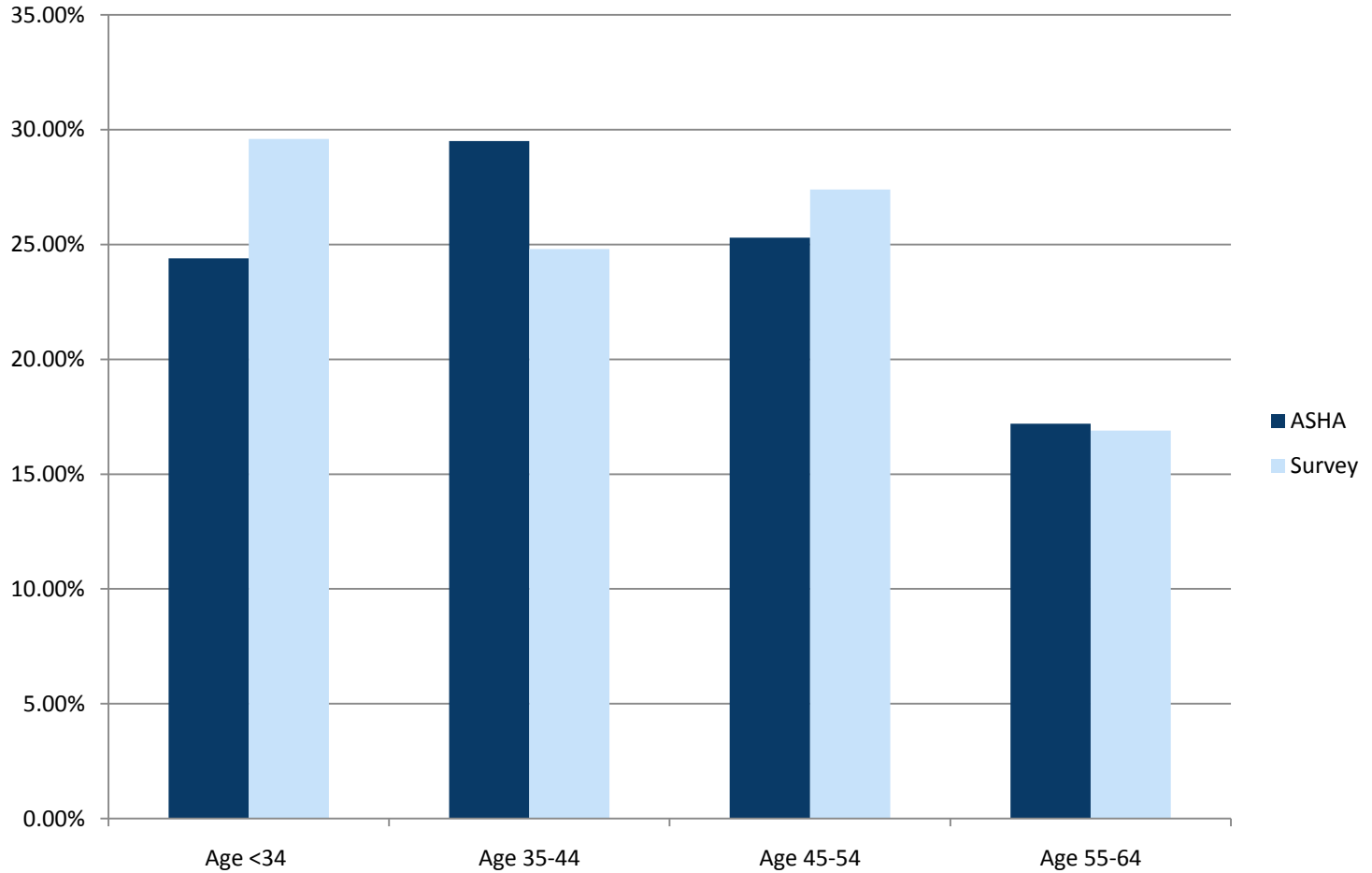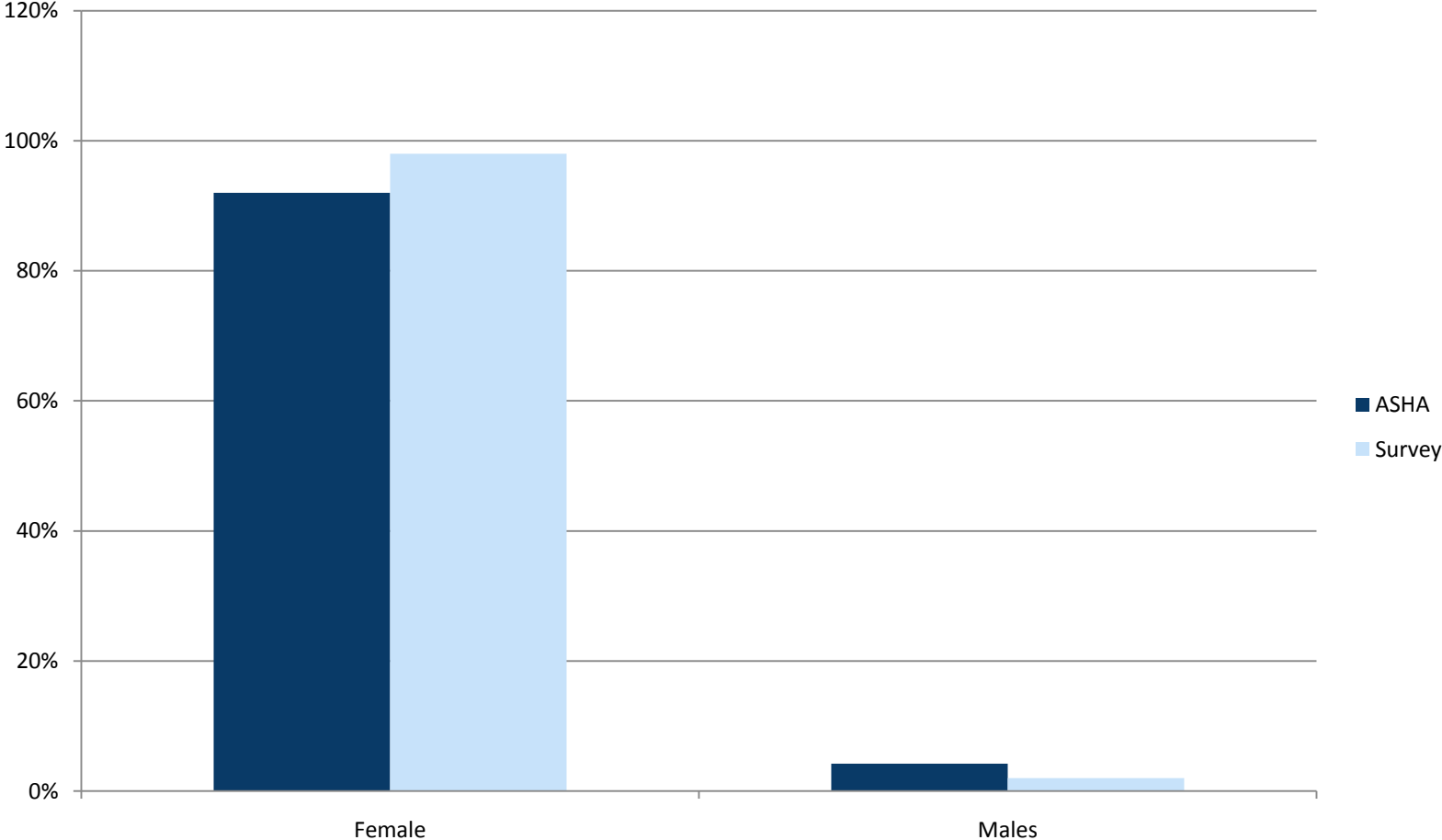
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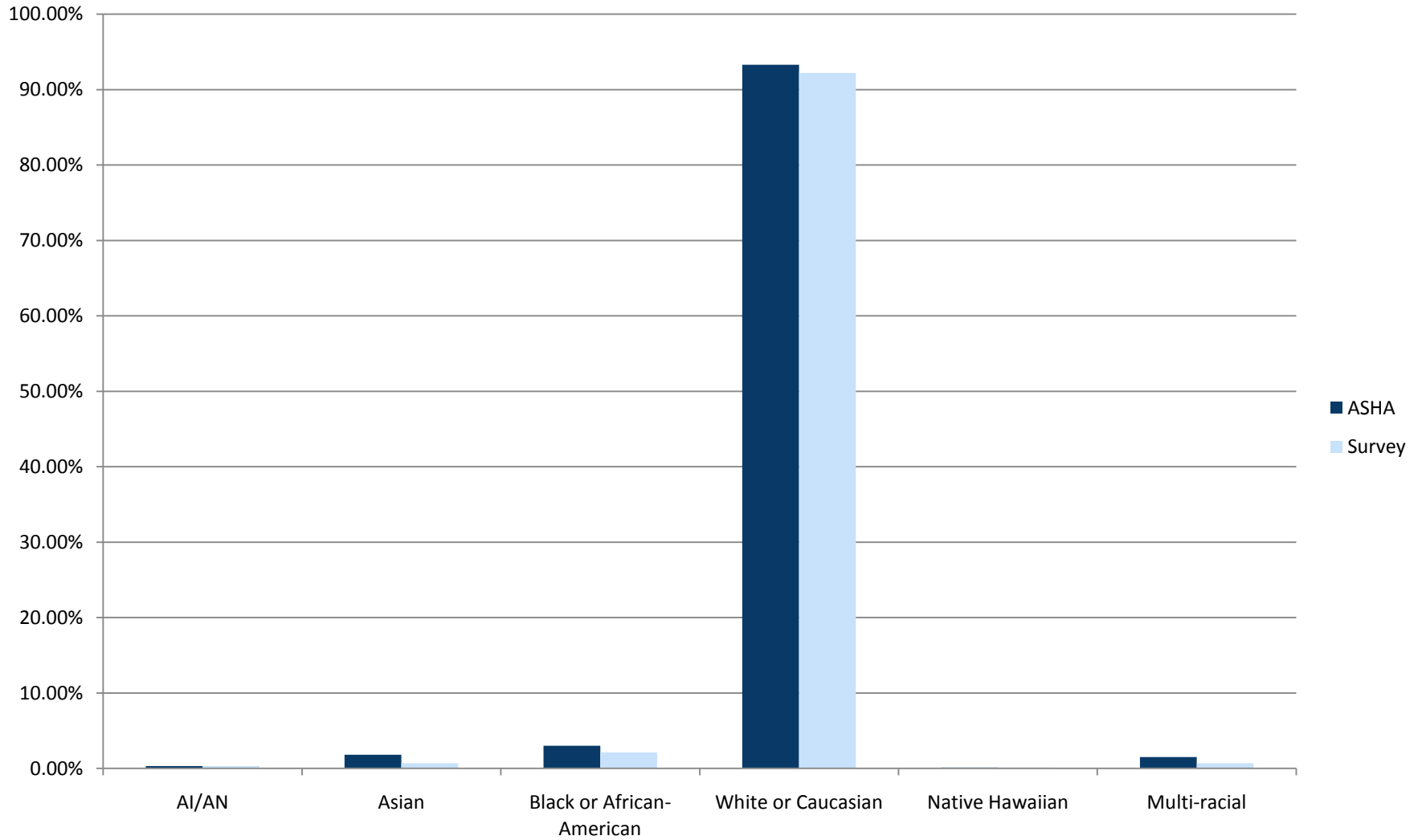
2073 Participants – Work Settings
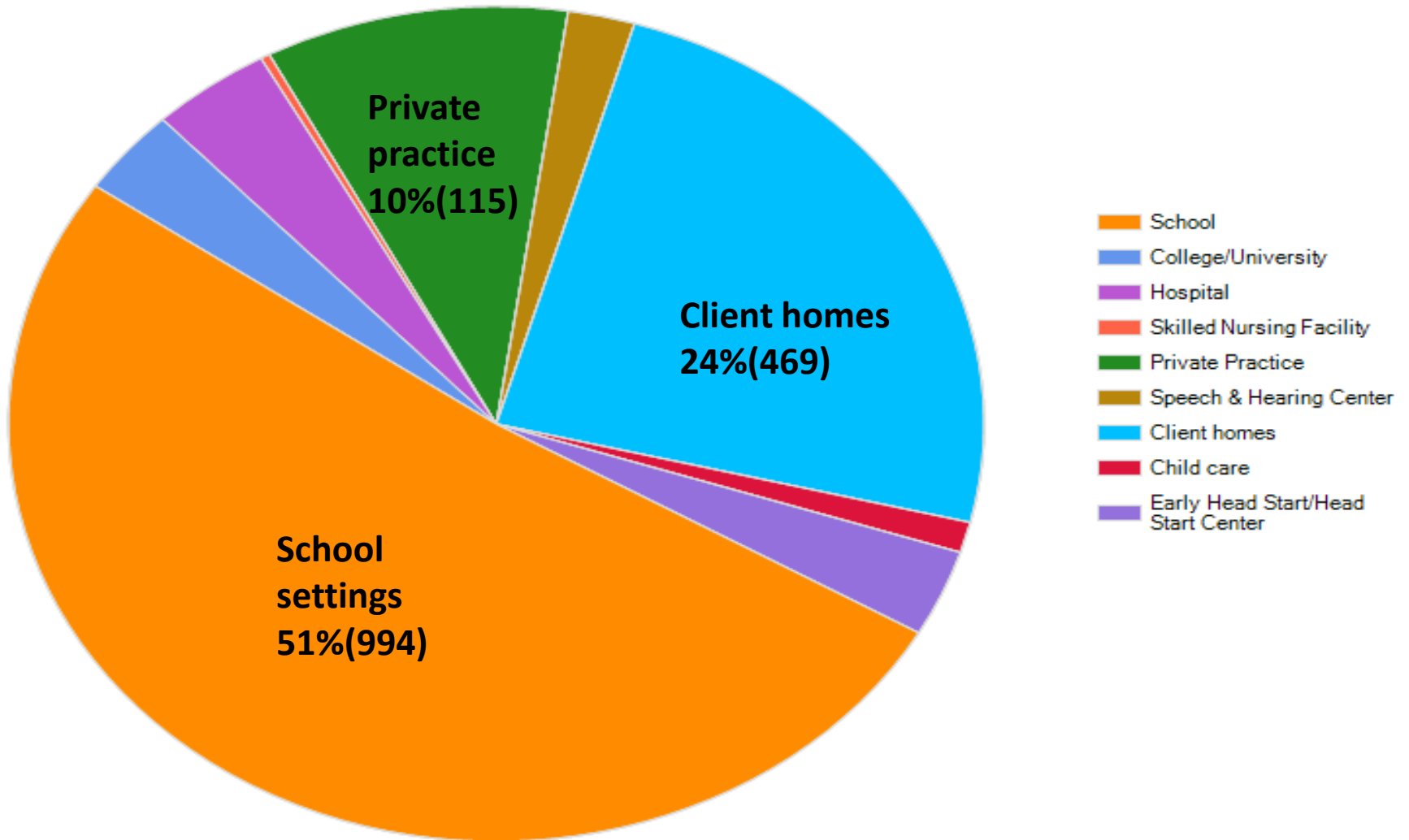
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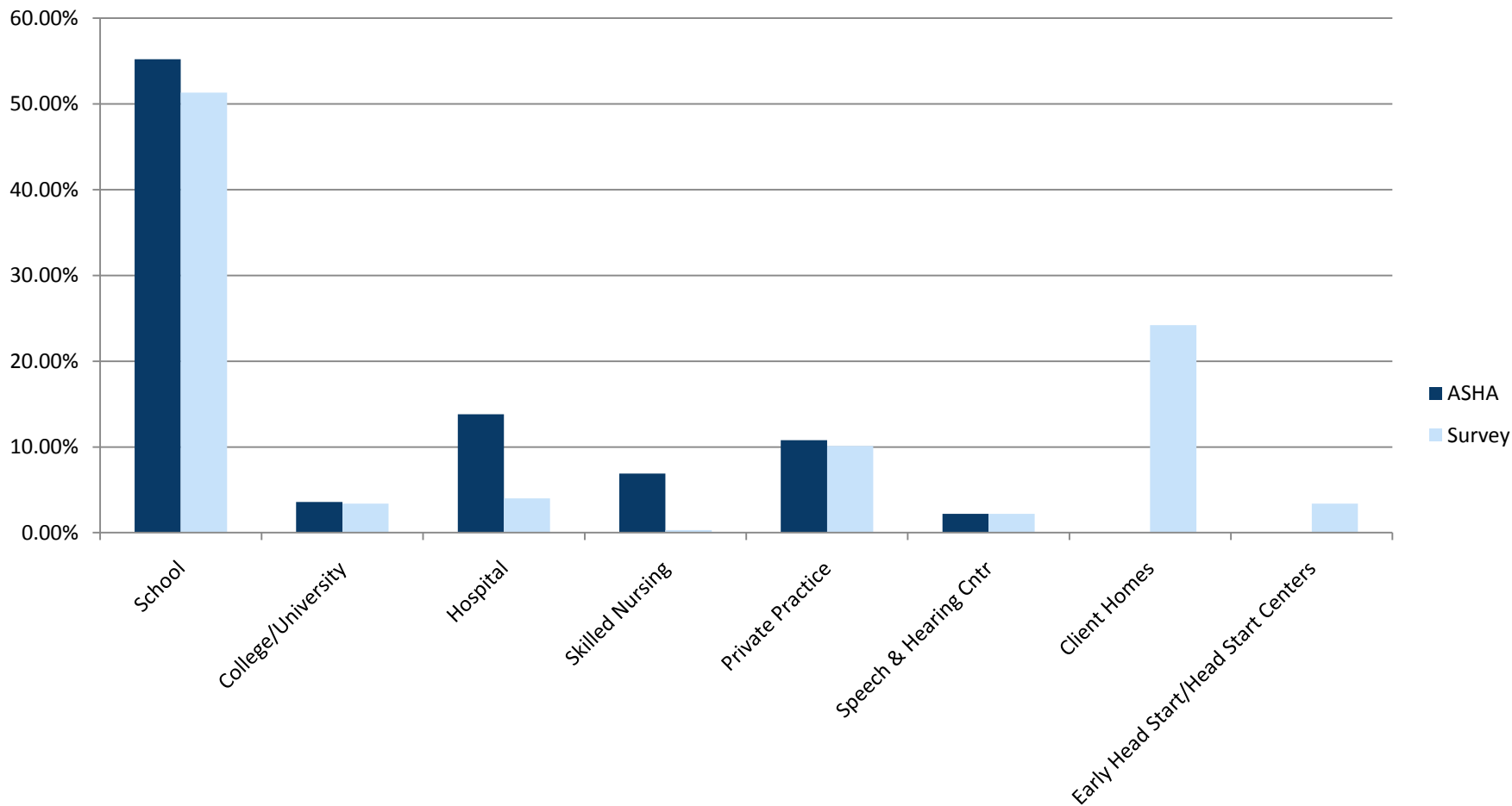
2073 Participants – Primary Job Role

90% (1,822) Service providers

Legend:
- Service Provider
- Teacher or Professor
- Researcher
- Consultant
- Student
- Administrator
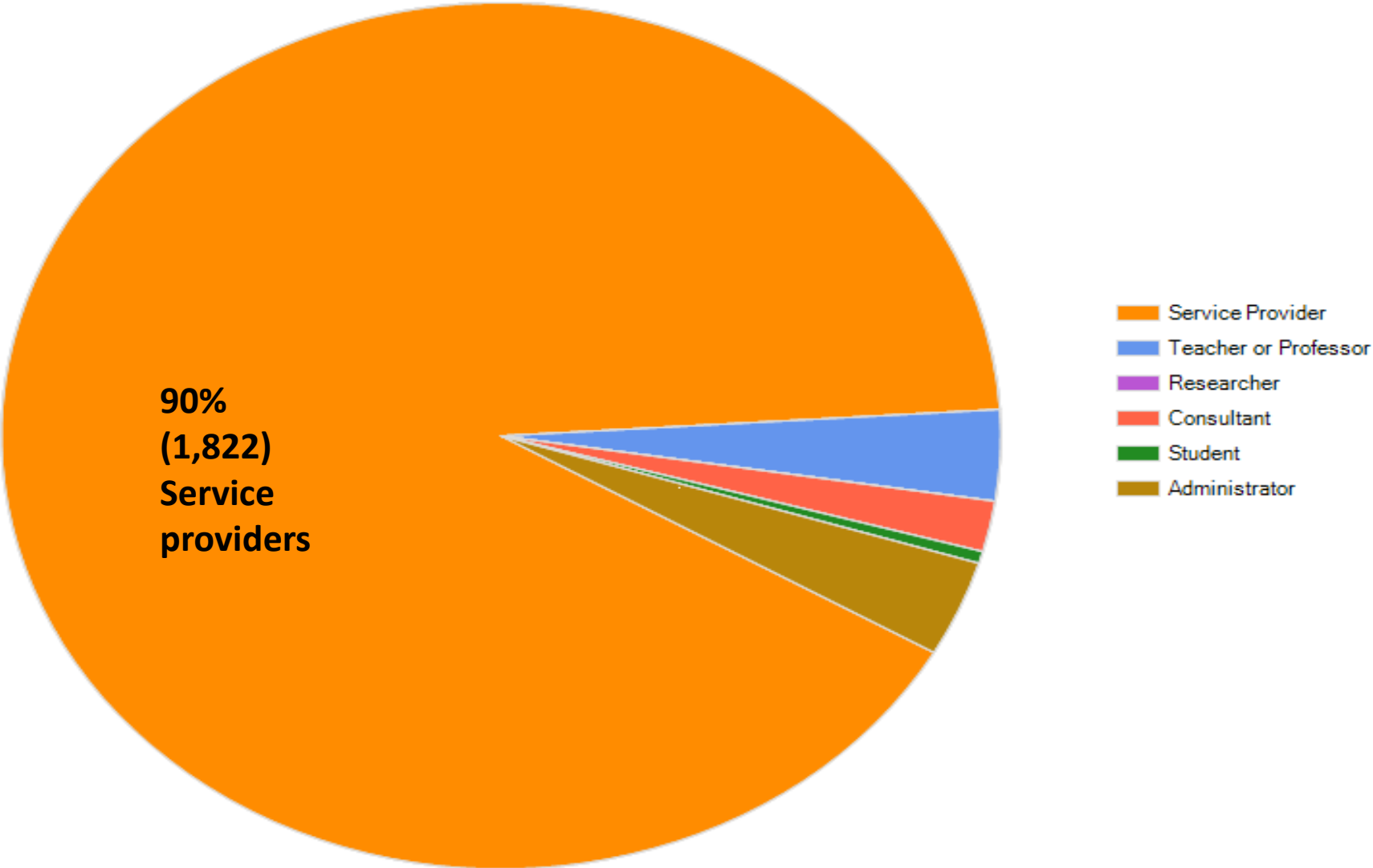
2073 Participants – by state
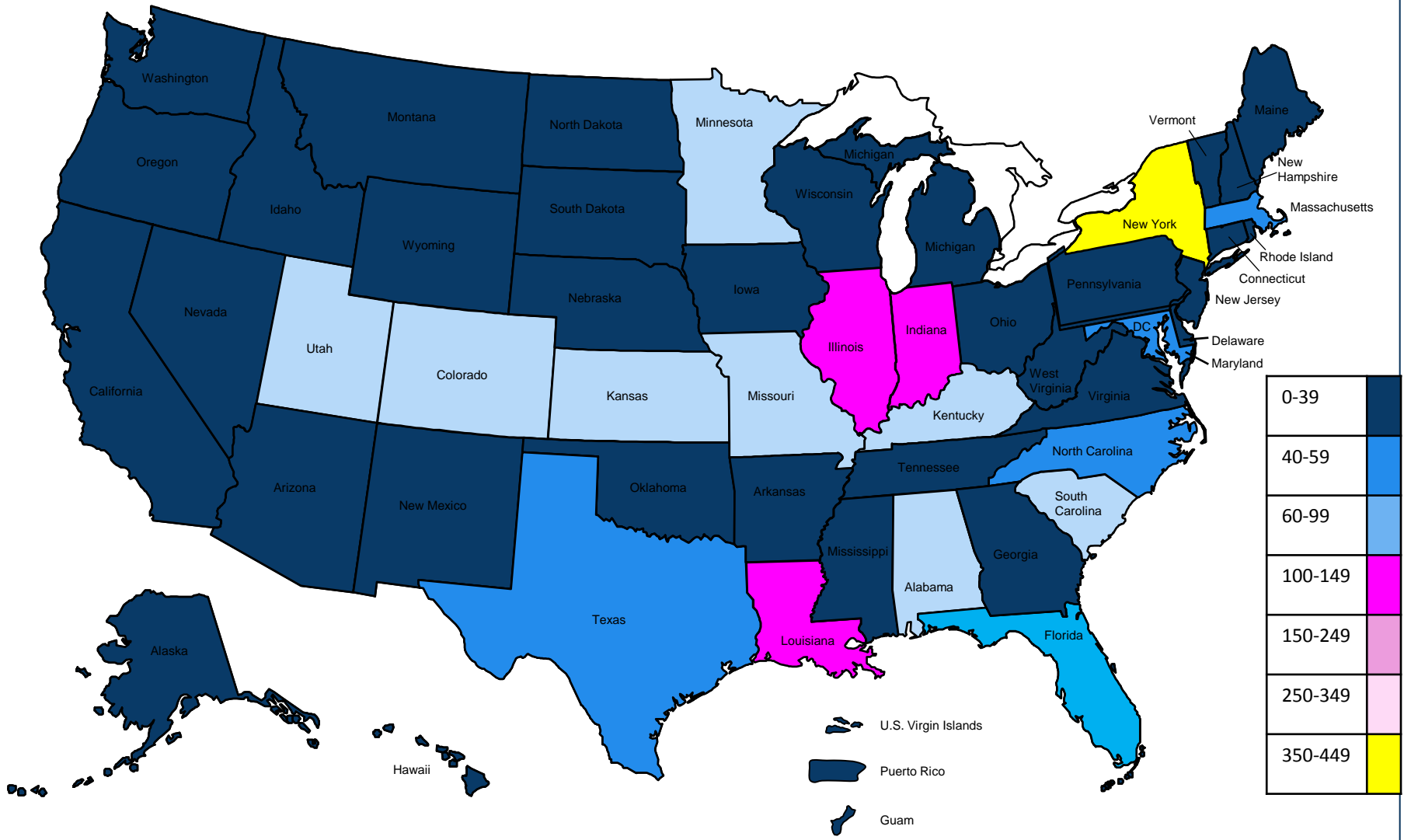
Range
0-39
40-59
60-99
100-149
150-249
250-349
350-449

2073 Participants – Geographic Area
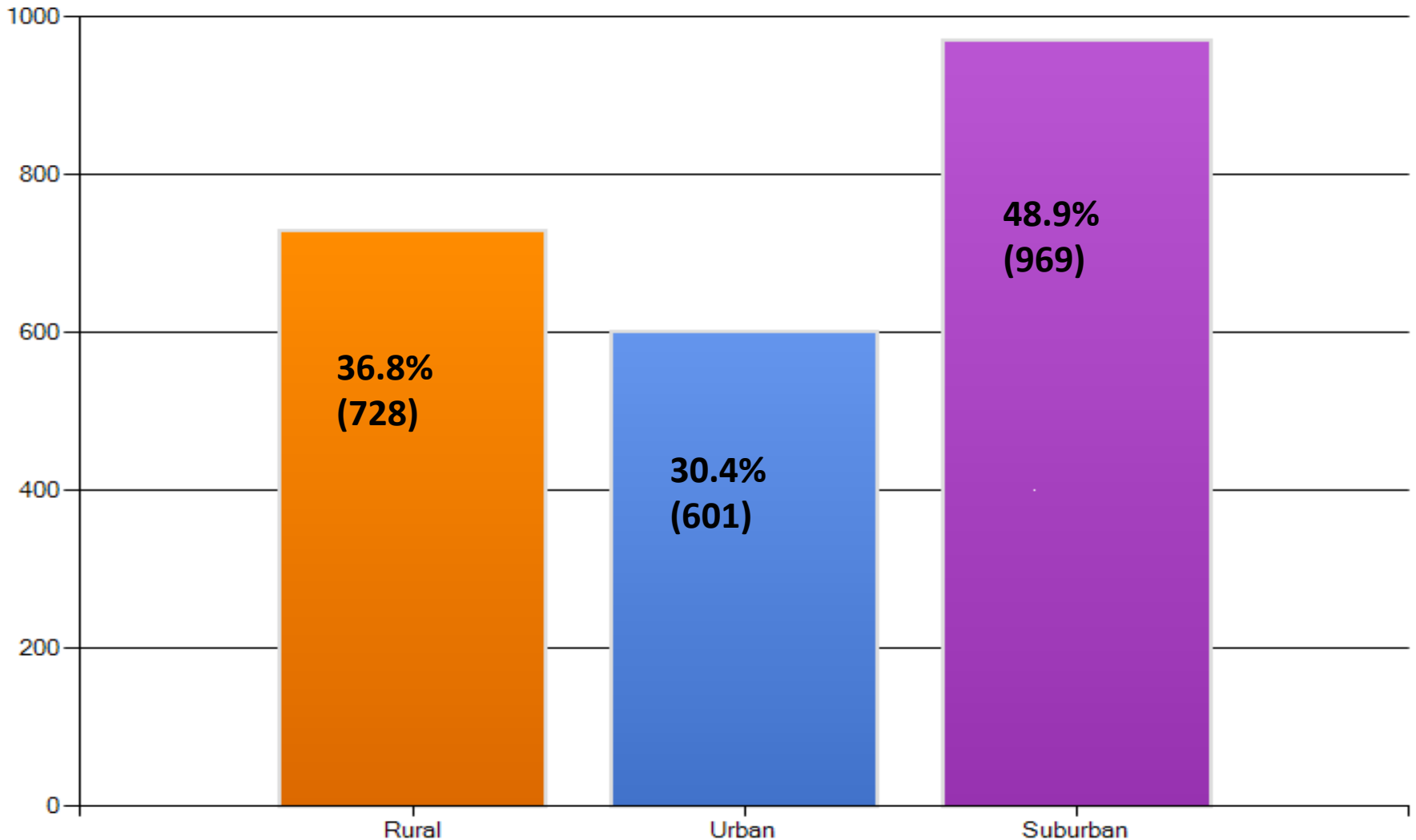
PRELIMINARY FINDINGS

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**

What SLPs do now

When testing, I informally screen for autism

When testing, I use published screeners designed to detect children who may be at-risk for autism — **47.67% (870)**

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

I have information to educate parents about monitoring their child's communication, cognitive,...

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

The number of families who ask about autism has increased

Families ask for information about developmental delays such as autism

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

Families ask for information about normal developmental milestones

- Strongly Agree N
- Agree N
- Disagree N
- Strongly Disagree N

0   500   1000   1500

What SLPs do now – key points

Many SLPs <u>do not</u> 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
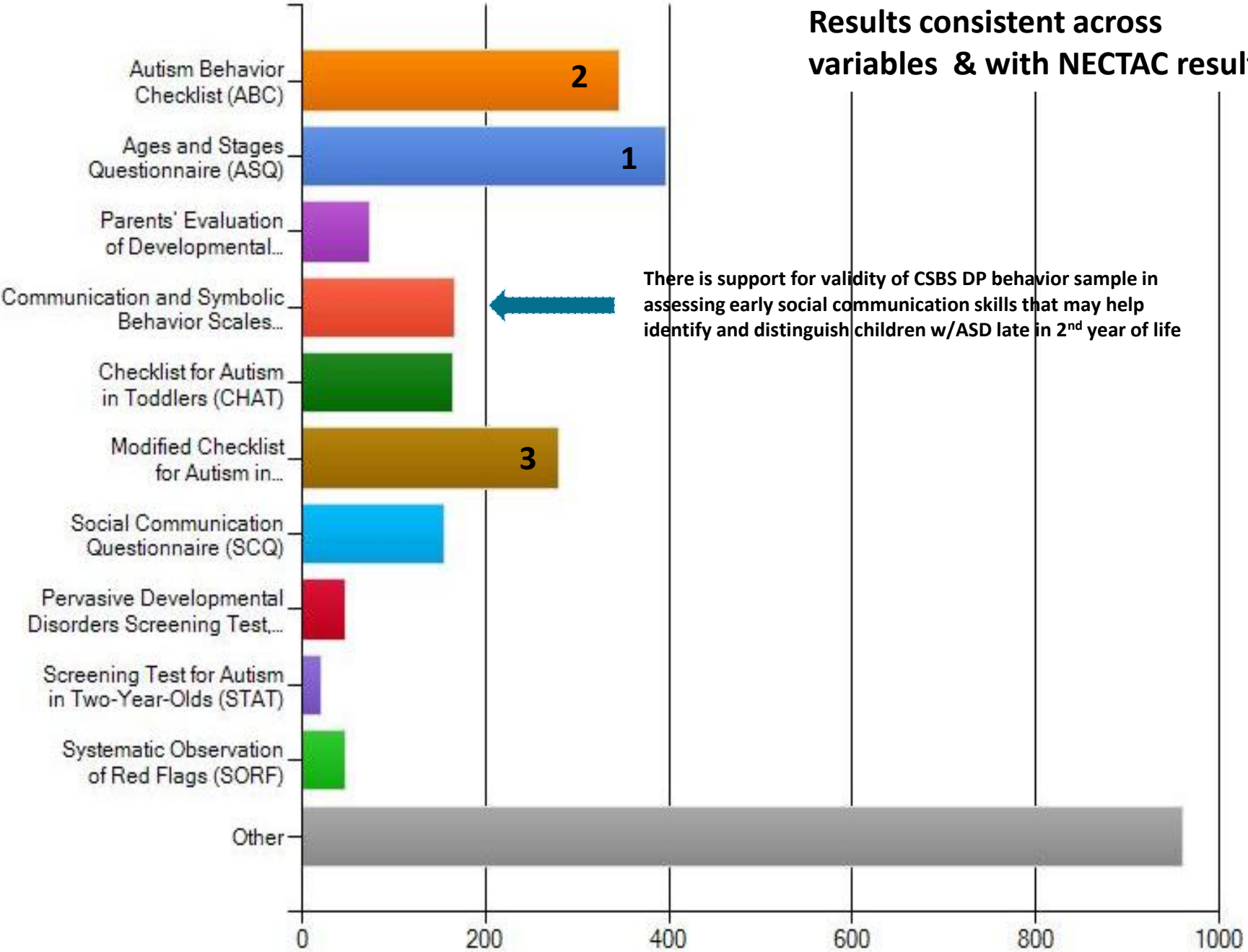
Screening is important for early identification. Easier to miss younger children-- indicators are not as obvious in young children

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 w/ASD late in 2nd year of life

Autism Behavior Checklist (ABC) — 2
Ages and Stages Questionnaire (ASQ) — 1
Parents' Evaluation of Developmental...
Communication and Symbolic Behavior Scales...
Checklist for Autism in Toddlers (CHAT)
Modified Checklist for Autism in... — 3
Social Communication Questionnaire (SCQ)
Pervasive Developmental Disorders Screening Test,...
Screening Test for Autism in Two-Year-Olds (STAT)
Systematic Observation of Red Flags (SORF)
Other

0   200   400   600   800   1000

When I suspect autism in a child, I usually refer the child and family to (select all that apply):

Legend:
- Part C, 0 to 3 early intervention system in my state
- Developmental pediatrician
- Neurologist
- Child psychiatrist
- Child psychologist
- Audiologist
- Another speech-language pathologist
- Autism school/clinic/treatment center
- Parent advocacy group
- Local school district
- Family pediatrician/physician

Chart labels:
- Family pediatricians/physicians 44.6%(306)
- Part C systems 53.6%(1,048)
- Developmental pediatricians 55.6%(1,087)

- 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:

Select and use screening tools for autism

Explain information about autism to families of differing cultures

Help families reach a diagnosis of autism (in general)

Discuss current evidence about autism with families

Access easy to read and appropriate resources about autism to share

Information SLPs would like to have

Top recommendations:	%
Current evidence in the field of autism	78%
Information for families about autism that is easy to read and understand	77.5%
Information about screening and screening tools for autism	76%
Methods for explaining information about autism to families of differing cultures	70.6%

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
- Journal articles
- Textbooks
- Colleagues/Specialists
- Professional meetings/conferences
- Pre-service/university graduate level training

How SLPs Acquire Information Now
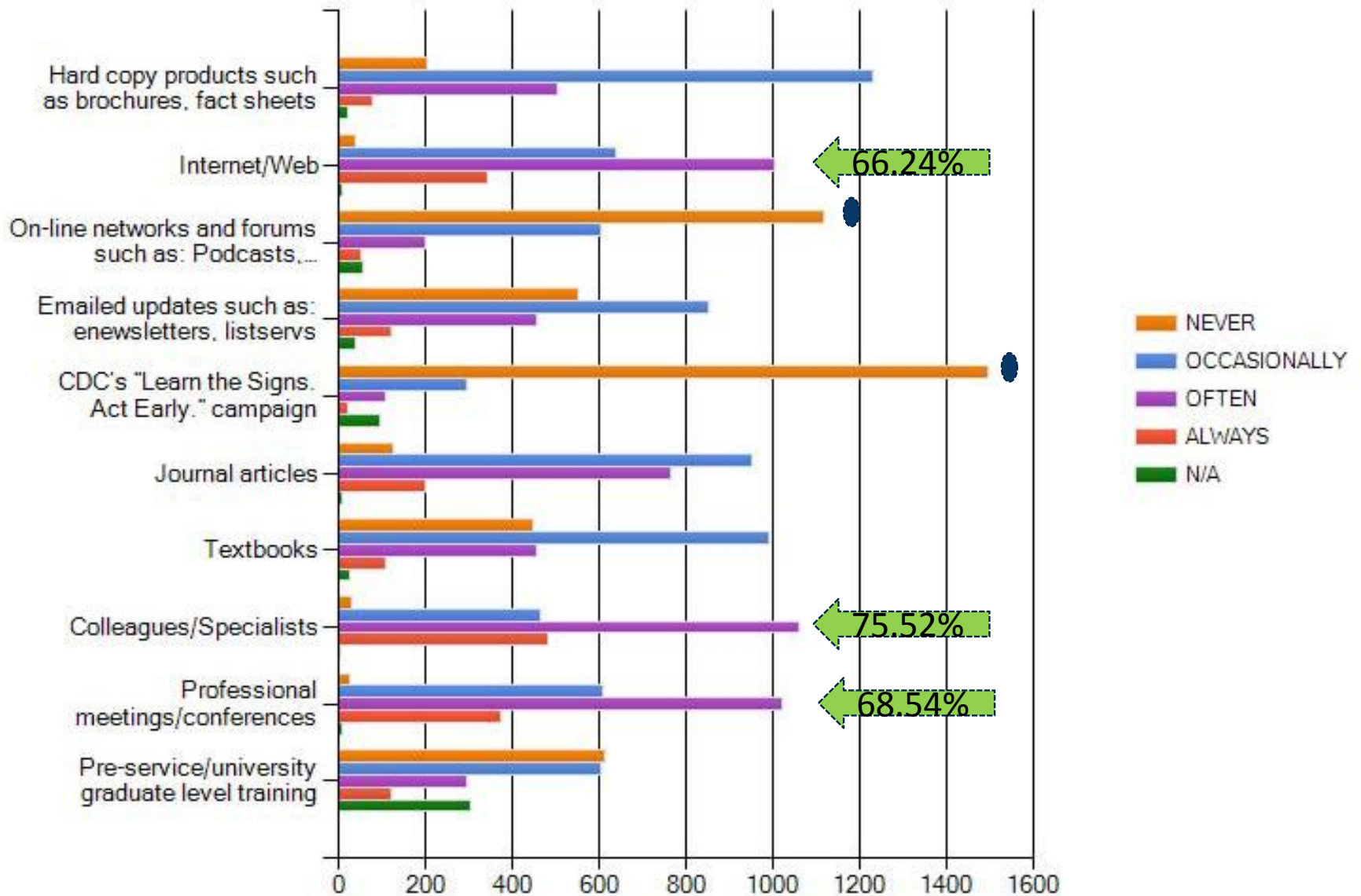
How SLPs acquire information now – key points

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

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%**

How SLPs prefer to receive information, cont'd

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. On-line 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; some not allowed to refer for further evaluation
- SLPs list a wide variety of tools used for screening

Comments

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

Comments

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

Comments

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?

Conferences, specialists, CDC & other websites, hard copies

Screening and referral

Resources for families: easy to read/understand, various types of support, & other individualized needs

More information for SLPs: current evidence, communicating with families, S/L indicators, role referral

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