

Identifying Barriers to Referrals for Assessment of Secondary Challenges in Children Who are Deaf/Hard of Hearing.

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Aim/Objective

Aim/Objective: To identify barriers in screening and assessment referrals for autism spectrum disorder (ASD) for children with restricted hearing.

Overview/Background

There is evidence to support the reliable identification of children on the autism spectrum by 2 years of age (Johnson et al., 2007), however symptoms of ASD may be exhibited and identifiable as young as 6-12 months of age (Charman & Baird, 2002; Mandell, Novak, & Zubritsky, 2005). As with other developmental disabilities, the goal is early intervention. In the US, the current average age of an ASD diagnosis in children with typical hearing is variable, however children are commonly not diagnosed until 4-5 years of age (Christensen et al., 2016; CDC, 2009).

The prevalence of ASD in the US is 1 in 68 children (CDC, 2009) and is estimated to be as much as three times higher in children with restricted hearing (Carr, Xu, Yoshinaga-Itano, 2014). In addition, children with restricted hearing are often late identified with secondary disabilities including ASD (Szarkowski, Mood, Shield, Wiley and Yoshinaga-Itano (2014). According to Meinzen-Derr et al. (2014), children with a dual diagnosis are diagnosed with hearing loss at a significantly younger age than the ASD diagnosis. The age of an ASD diagnosis is variable and can be delayed until adolescence or adulthood (Meinzen-Derr et al., 2014).

Overlapping Symptoms. The later age of diagnosis of ASD in children with a dual diagnosis could be due to the overlapping or similarity of symptoms and challenges often exhibited in children with hearing loss and in children with ASD. According to Szarkowski, Mood, Shield, Wiley, and Yoshinaga-Itano (2014), there are many symptoms that are associated with both conditions (see table). The overlapping symptoms are often difficult to identify because they can occur with both conditions and can be tied to hearing loss or ASD. Therefore ASD assessments are not sensitive or validated to children with hearing loss. In addition, the normative data on ASD screening tools do not consider hearing loss or alternative forms of communication (Carr, Xu, and Yoshinaga-Itano, 2014; Worley, Matson, and Kozlowski, 2011).

Overlapping Symptoms
Reduced eye contact
Not responding to name or attention getting measure
Limited show/give behaviors
Reduced gesture use
Lack of pointing for shared enjoyment
Reduced joint attention
Poor imitation skills
Problems with turn taking
Problems with making choices
Difficulty engaging in social communication
Abnormal prosody of speech/sign
Limited spontaneous language use

Red Flags: The later age of diagnosis of ASD in children with a dual diagnosis could also be due to the lack of knowledge of ASD red flags and/or a lack of awareness of referral resources. The Modified Checklist for Autism in Toddlers (M-CHAT) is a commonly used screening tool for ASD and identifies common symptoms (see table). Results obtained from a retrospective chart review conducted by Szarkowski et al. (2014) found that individual professionals vary significantly in their comfort in giving a dual diagnosis of autism with hearing loss as well as their level of knowledge of the red flags. This study highlights the need for further resources and training of providers who work with children so they are aware that there is a possibility of a dual diagnosis. It is important for professionals to understand the ways in which ASD presents in children who are deaf and hard of hearing.

Red Flags
Lack of social smiles or sharing joyful expressions directed at people
No babbling
Any loss of previously acquired speech, babbling, or social skills
No gestures to communicate
No words
Pronoun avoidance
Has unusual, intense reaction to sounds, smells, tastes, textures, lights, and/or colors
Repeats words/phrases over and over

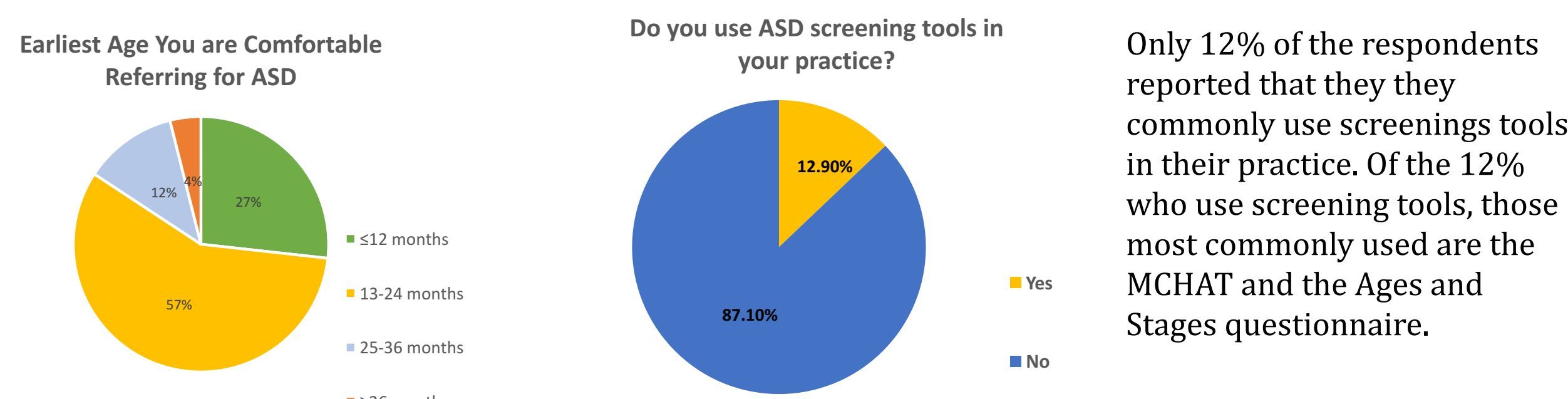
Professional variables: There are multiple barriers to accurate and timely secondary diagnosis including provider expertise and a lack of trusted follow-up assessment services. This project was designed to identify information that could be helpful in reducing barriers to referrals for assessment of secondary challenges. Knowledge of current practices and referral patterns can be used to provide education, information, and resources designed to support the needs of professionals providing services to children with restricted hearing and ASD. The ultimate goal of this investigation is to reduce the age of identification of a dual diagnosis in children with restricted hearing.

Methods

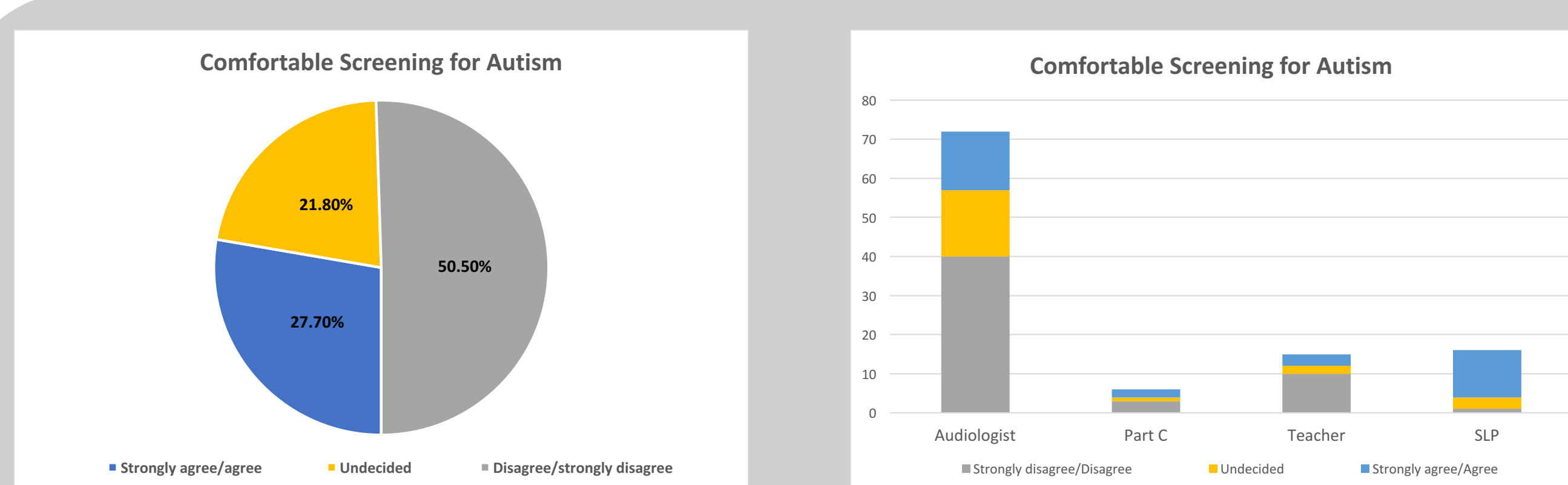
This survey was designed to determine professional awareness, knowledge, protocols, and available resources for referral options for an ASD diagnosis in children with restricted hearing. The questions included in the survey were designed using a matrix and forced choice format. The survey was developed in RedCap and was distributed electronically via listservs and social media. Professionals who work in the Colorado Home Intervention Program, in public schools in Colorado, and members of the Colorado Academy of Audiology were all sent survey requests through specific email list serves. In addition, survey information was distributed on Facebook. It is estimated that approximately 500-600 professionals received the survey. Completed surveys were received from 101 individual professionals with an estimated response rate of 17-20%. Survey data analysis was completed using RedCap and Excel software.

Results

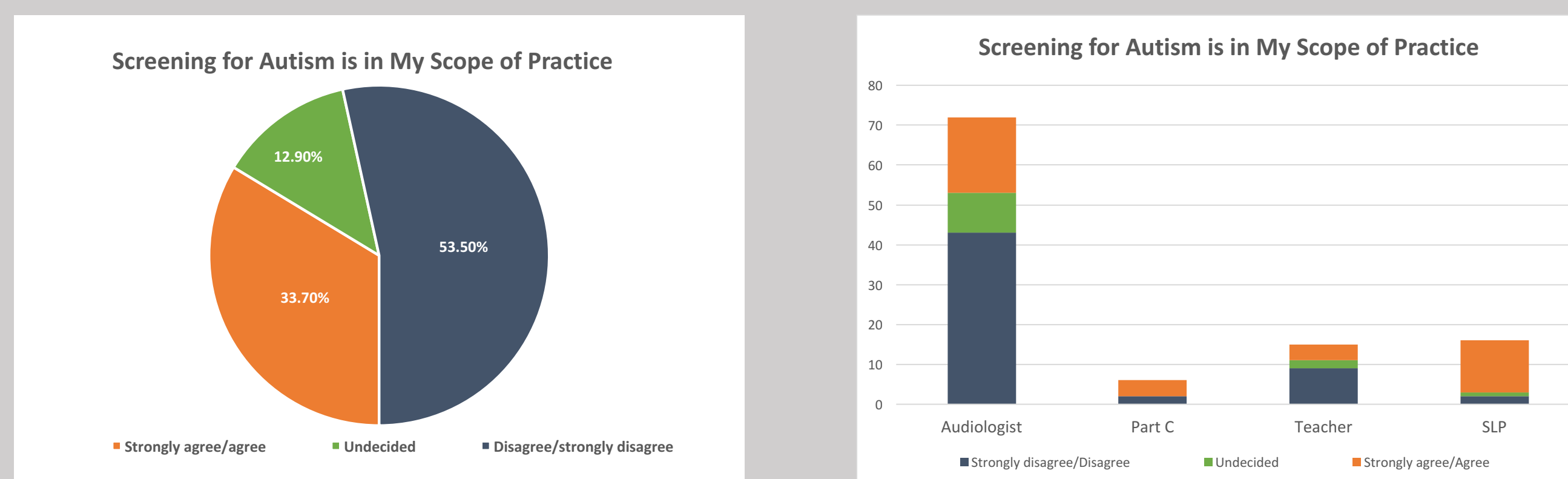
There were 101 complete responses to the survey. The respondents identified their professional working environment as either an educational setting, a medical setting, in-home services, and independent practices. In regards to their educational background specific to ASD, respondents were asked to identify all areas in which they gained ASD specific education: 90 respondents selected direct experience, 90 respondents selected direct instruction, and 48 respondents selected independent learning.



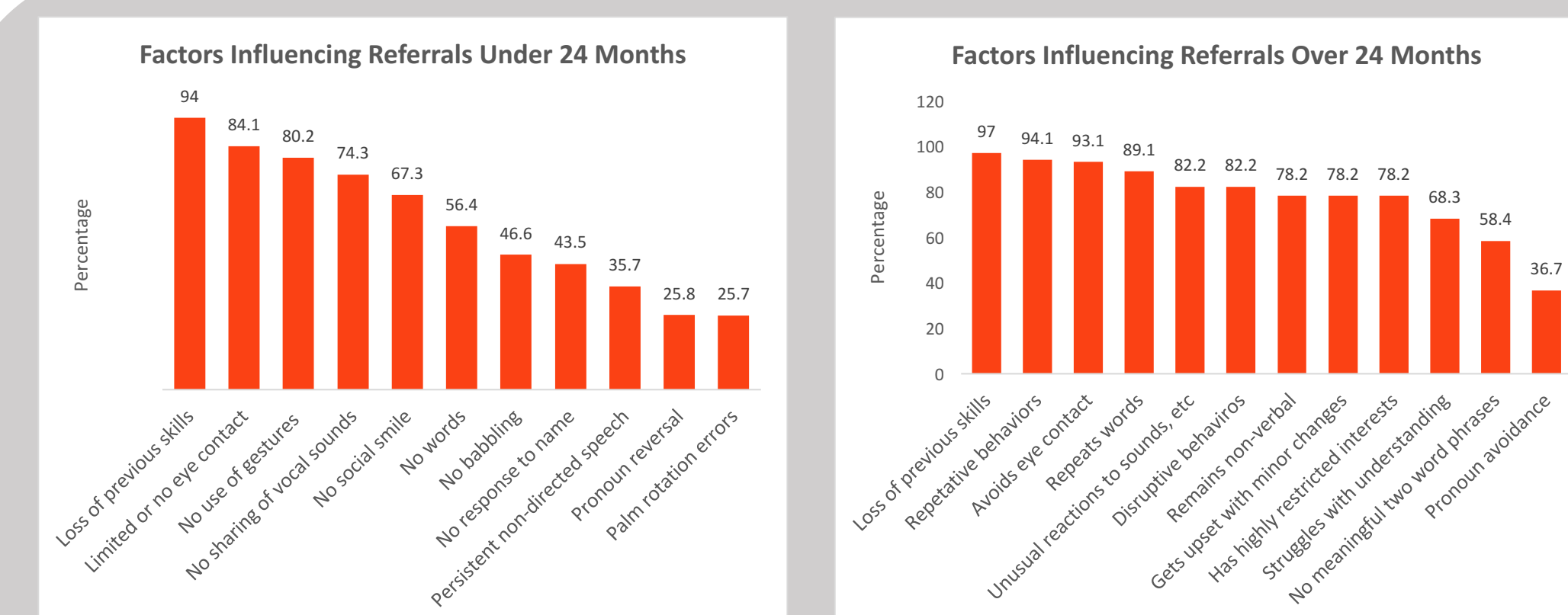
Only 12% of the respondents reported that they commonly use screenings tools in their practice. Of the 12% who use screening tools, those most commonly used are the MCHAT and the Ages and Stages questionnaire.



More than half of respondents indicated they were not comfortable screening for autism. Approximately 50% of audiologists, part C providers, and early interventionists are not comfortable screening for ASD, however only 6% of SLPs are not comfortable screening for ASD.



More than half of respondents do not think screening for ASD in within their scope of practice. Approximately 60% of audiologists and teachers of the deaf do not think screening is within their scope of practice, however approximately less than 20% of part C providers and SLPs do not think screening is within their scope of practice.



Percentage of people rating the factor as a high concern; 94% of respondents indicated that the loss of previous skills was a high concern for referral under 24 months, 97% of respondents indicated that the loss of previous skills was a high concern for referral over 24 months.

Factors influencing referral patterns were analyzed and significant findings include: 73.3% of respondents indicate degree of hearing loss would influence an ASD referral, 80.2% indicate degree of language delay would influence an ASD referral, and 99% indicate they have access to qualified professionals to refer for an ASD evaluation.

Discussion

Research shows that the age of autism diagnosis tends to occur significantly after the identification of the child's hearing loss and later than in the hearing population (Szarkowski et al, 2014). The advent of newborn infant hearing screening procedures and specialized early intervention services for children with restricted hearing has resulted in early professional support. Therefore, professionals working with young children recognize and identify communication challenges resulting from hearing loss and ideally have the ability to recognize and identify non-hearing specific challenges also at a early age. In theory, allowing for earlier identification of ASD in this population (Mood, & Shield; 2014). Unfortunately the results from this survey, as well as previous research, indicate that there are several factors and barriers that complicate an earlier dual diagnosis.

Significant Barriers to Early Dual Diagnosis

1. The majority of the responding providers reported that screening for autism was not in their scope of practice or their comfort level. This finding suggests that autism specific training may be necessary for these professionals.
2. The providers reported awareness and knowledge of the red flags of ASD and there is agreement about which factors are important for a referral. However, they are generally not using screening tools in their practice and over 50% are not comfortable using using those tools. Without a process to identify and refer, children may not receive a timely diagnosis.
3. All providers indicated that they would like more resources to be available.

Results from this survey indicate that to improve the age of dual diagnosis, many providers could benefit from ASD specific education and resource identification to improve their knowledge and understanding. Colorado Audiology LEND trainees have identify the need for a "road map" of steps for families and professionals to follow in order to navigate the system of a dual-diagnosis and a list of resources available in Colorado

References

Carr, J., Xu, D., & Yoshinaga-Itano, C. (2014). Language Environment Analysis Language and Autism Screen and the Child Development Inventory Social Subscale as a possible autism screen for children who are deaf or hard of hearing. In *Seminars in speech and language* (Vol. 35, No. 04, pp. 266-275). Thieme Medical Publishers.

Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology and Psychiatry*, 43(3), 289-305.

Christensen, D. L., Bilder, D. A., Zahorodny, W., Pettigrove, S., Durkin, M. S., Fitzgerald, R. T., Rice, C., Kurius-Spencer, M., Ballo, J., & Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *Journal of Developmental & Behavioral Pediatrics*, 37(1), 1-8.

Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183-1215.

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116(6), 1480-1486.

Meinzen-Derr, J., Wiley, S., Bishop, S., Manning-Courtney, P., Choo, D. L., & Murray, D. (2014). Autism spectrum disorders in 24 children who are deaf or hard of hearing. *International Journal of Pediatric Otorhinolaryngology*, 78(1), 112-118.

Mood, D., & Shield, A. (2014, November). Clinical use of the Autism Diagnostic Observation Schedule—Second Edition with children who are deaf. In *Seminars in Speech and Language* (Vol. 35, No. 04, pp. 288-300). Thieme Medical Publishers.

Szarkowski, A., Mood, D., Shield, A., Wiley, S., & Yoshinaga-Itano, C. (2014). A summary of current understanding regarding children with autism spectrum disorder who are deaf or hard of hearing. In *Seminars in speech and language* (Vol. 35, No. 04, pp. 241-259). Thieme Medical Publishers.

Szarkowski, A., Flynn, S., & Clark, T. (2014). Dually diagnosed: A retrospective study of the process of diagnosing autism spectrum disorders in children who are deaf and hard of hearing. In *Seminars in speech and language* (Vol. 35, No. 04, pp. 301-308). Thieme Medical Publishers.

Worley, J. A., Matson, J. L., & Kozlowski, A. M. (2011). The effects of hearing impairment on symptoms of autism in toddlers. *Developmental neurorehabilitation*, 24(3), 171-176.

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