

National Stuttering Association Members' Opinions About Stuttering Treatment.

Old Title: Where do people who stutter seek treatment?

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Purpose

- To present results of a survey of National Stuttering Association (NSA) members' opinions regarding issues of importance to speech-language pathologists (SLPs)
 - Where do people who stutter go to get information about stuttering treatment?
 - What do people who stutter think are the best settings, schedules, and goals for treatment?
 - What opinions do people who stutter hold about resources that are available to them?

Stuttering Support Groups

- Stuttering support groups are playing an increasingly important role in the **recovery** process for many people who stutter
 - Interestingly, although stuttering support groups have been available for more than 20 years, the professional community has only recently begun to explore partnerships with support groups
- **The increased role of support groups has several important **implications** for SLPs who work with people who stutter**

Efficacy of Support Groups

- If support group participation is viewed as a part of the treatment process, then we must evaluate the **efficacy** of that participation, just as we evaluate the efficacy of treatment
 - There is ample anecdotal evidence that people who stutter experience benefits from support groups; however, empirical research is needed
 - The NSA has recently begun a series of studies about the benefits of support group participation (see Yaruss et al., 2001 for more information)

Influence of Support Groups

- Support groups can have a strong influence on the opinions of people who stutter
 - Support group members receive newsletters, literature, and other information about stuttering, stuttering support, and stuttering treatment
 - This information can have a strong effect on the opinions people who stutter have about the field of speech-language pathology
- SLPs have a vested interest in providing accurate information to support groups

Visibility of Support Groups

- As stuttering support groups gain visibility, they are becoming an increasingly important resource for people who stutter who may be seeking information about treatment
 - Many support groups (e.g., NSA, BSA, CAPS, ELSA) have a growing presence on the internet
 - Support groups are often mentioned in newspaper and news stories, along with ASHA and the SFA
 - Many groups publish their own literature
(See the new materials at the NSA booth!)

Power of Support Groups

- Larger and more powerful consumer organizations will play a greater role in the development of **policies**, e.g.,
 - Insurance coverage for stuttering treatment
 - Availability of different types of treatment
 - Education of SLP students
- As the opinions of support group members become more **prominent**, it is important for SLPs to become aware of those opinions and learn to work with support groups

Opinions of Support Group Members

- There are several compelling reasons for clinicians and researchers to understand the opinions of support group members
 - What resources do they consult when seeking information about treatment?
 - What advice do they provide to each other regarding treatment, early intervention, etc.?
- Little is presently known about the opinions of support group members – ***the purpose of this study was to gather such information***

Method: The Survey

- Questionnaire contained 13 questions addressing respondents opinions about...
 - Where they would get information if they were interested in treatment, and where they might go for treatment...
 - What recommendation they would give to a friend with a child who stuttered, and what they would do if their own child stuttered...
 - What is the most appropriate setting, schedule, and goals of treatment for children and adults...
 - What is the value of available resources...

Method: Participants

- 200 members of the NSA support group
 - Original subject pool included 500 members who received the questionnaire by mail
 - 225 responded to the survey, 25 were SLPs, so they were excluded from this analysis
- Of the 200 respondents...
 - 176 were people who stutter
 - 56 were family members of people who stutter
 - 33 were people who stutter *and* family members
 - 7 were people who stutter *and* SLPs

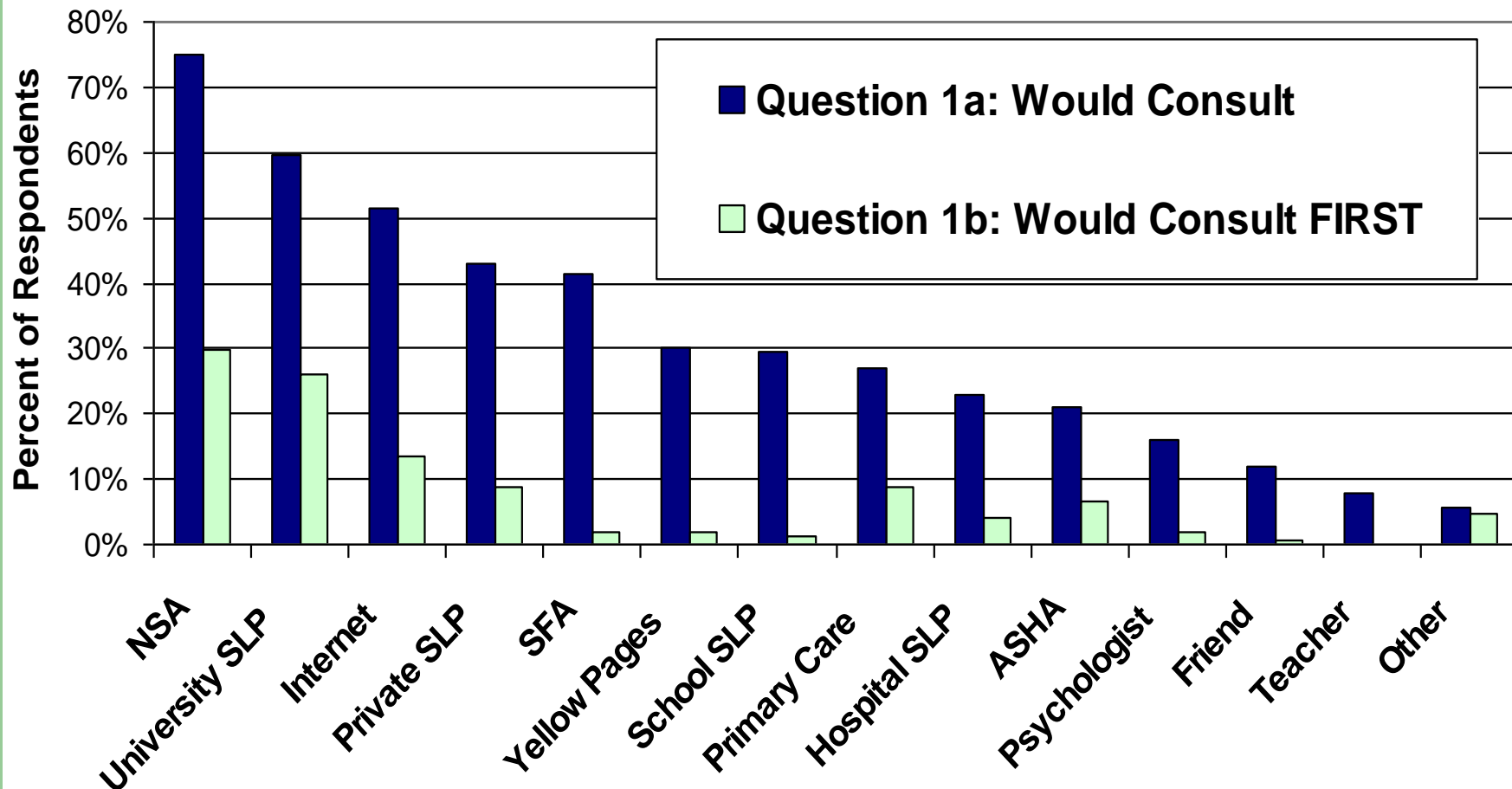
Method: Participants

- Of course, this sample is highly self-selected
 - People who stutter who choose to be in the NSA
 - People who took time to respond to the survey
- However, the goal of this research (and other studies in this program) is to study people who participate in support groups
 - Additional studies will also be undertaken in the future to examine people who do not participate in support groups to allow direct comparisons

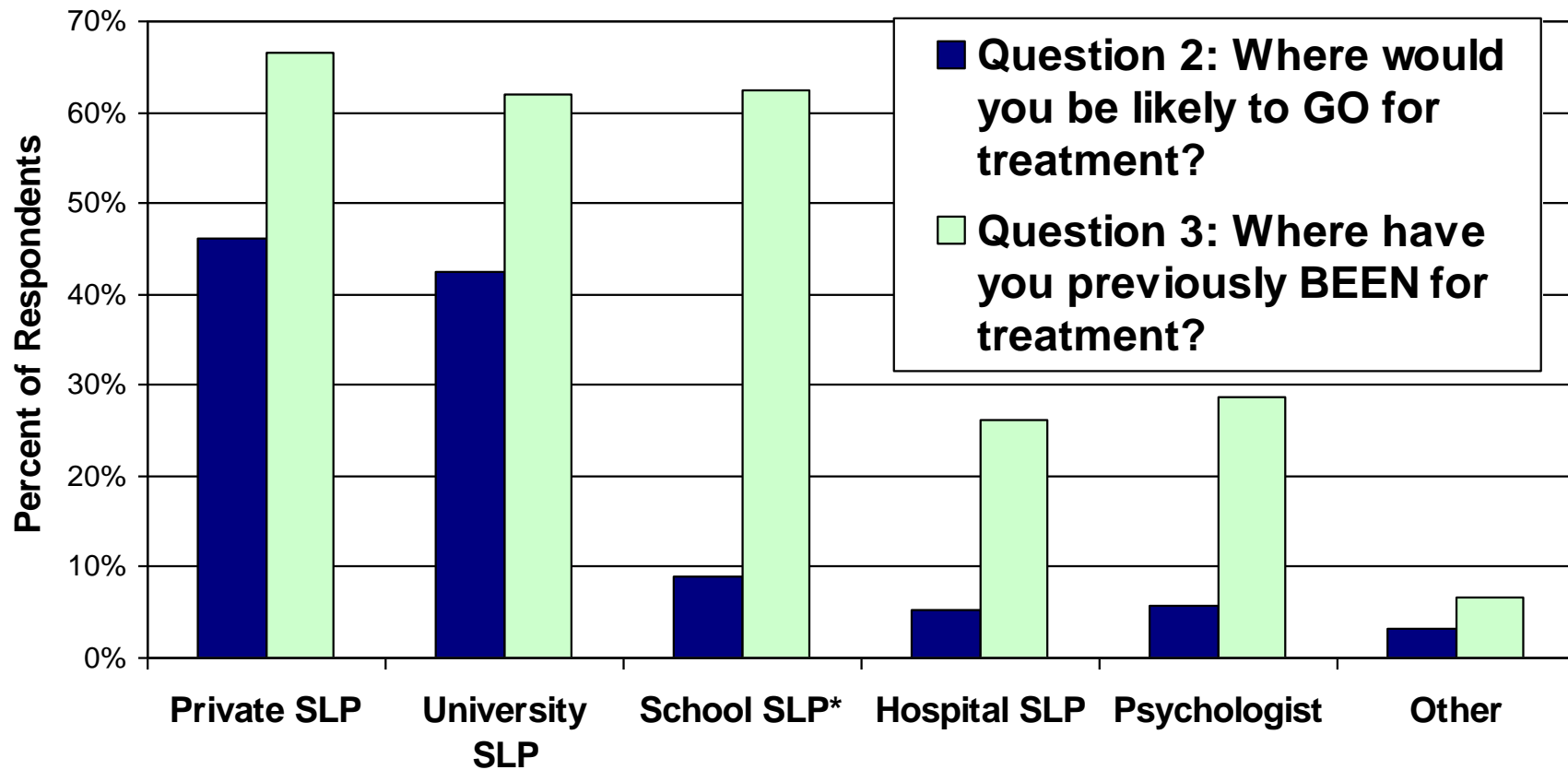
Self-Referral Practices

- **Q1:** If you were interested in speech therapy (for yourself or a family member), what **sources** would you consult for information?
 - 1a: Check all that apply, then
 - 1b: circle the one you would go to *first*.
- **Q2:** If you decided to obtain therapy (for yourself or family member), where would you be most likely to **go**? (Check only one.)
- **Q3:** Where have you (or family) received therapy in the past? (Check all that apply.)

Question 1a, 1b



Questions 2 and 3



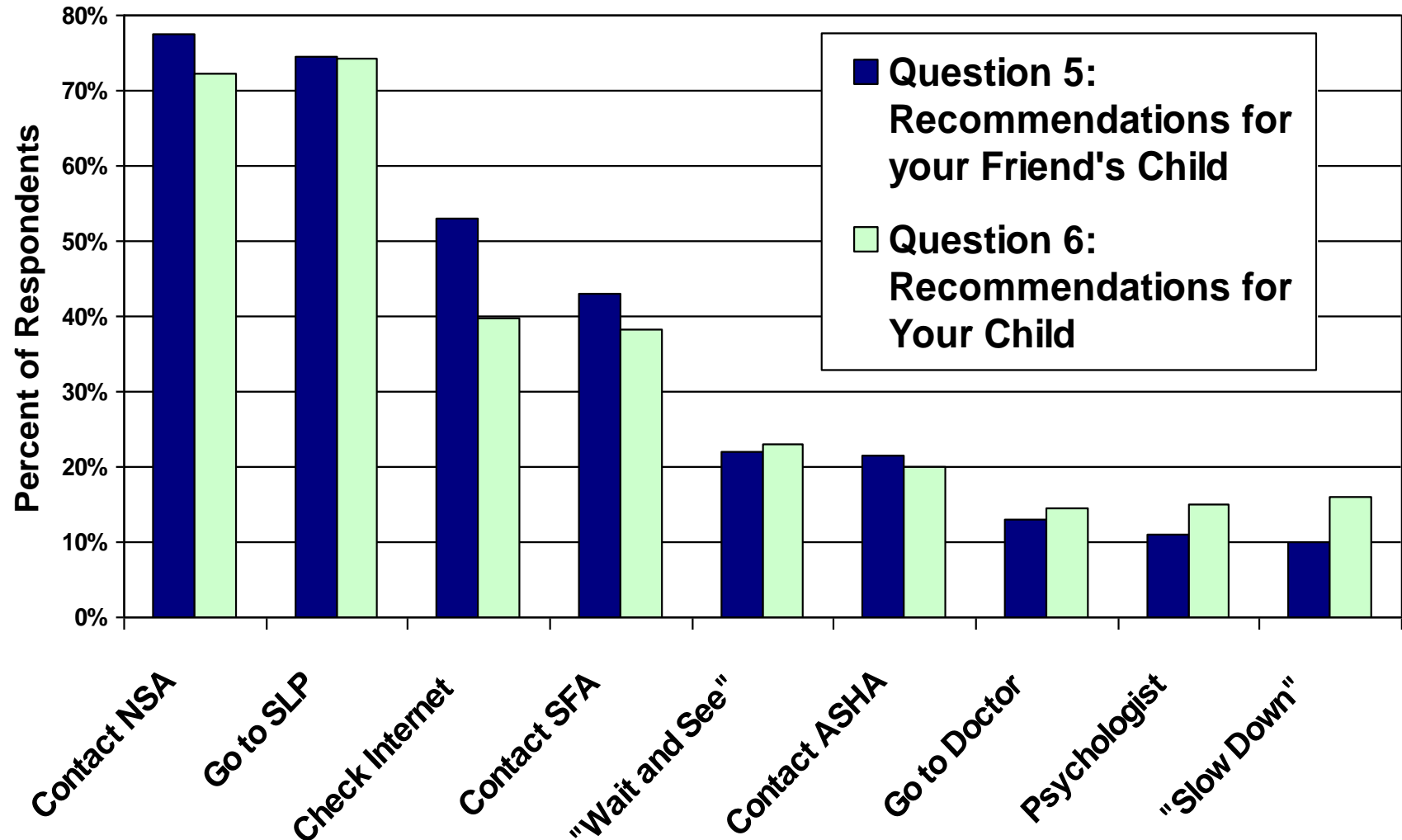
History of Treatment

- **Q4:** At what ages have you (or your family member) received therapy? (Check all that apply.)
 - Respondents had treatment at a variety of times
 - 15.9% as preschoolers
 - 74.4% in school-age years
 - 66.2% as adults
 - 65% marked more than one age range
- The finding that fewer NSA members recalled treatment in preschool is consistent with prior research on the NSA (Yaruss et al., 2001)

Early Intervention

- Q5: If your friend had a child who stuttered, what would you recommend they do? (Check all that apply.)
- Q6: If you had a child who stuttered, what would you do? (Check all that apply.)
- *Note: These questions were examined separately to determine whether respondents would treat their own children differently because they were people who stutter or were familiar with people who stutter because of their involvement in the NSA.*

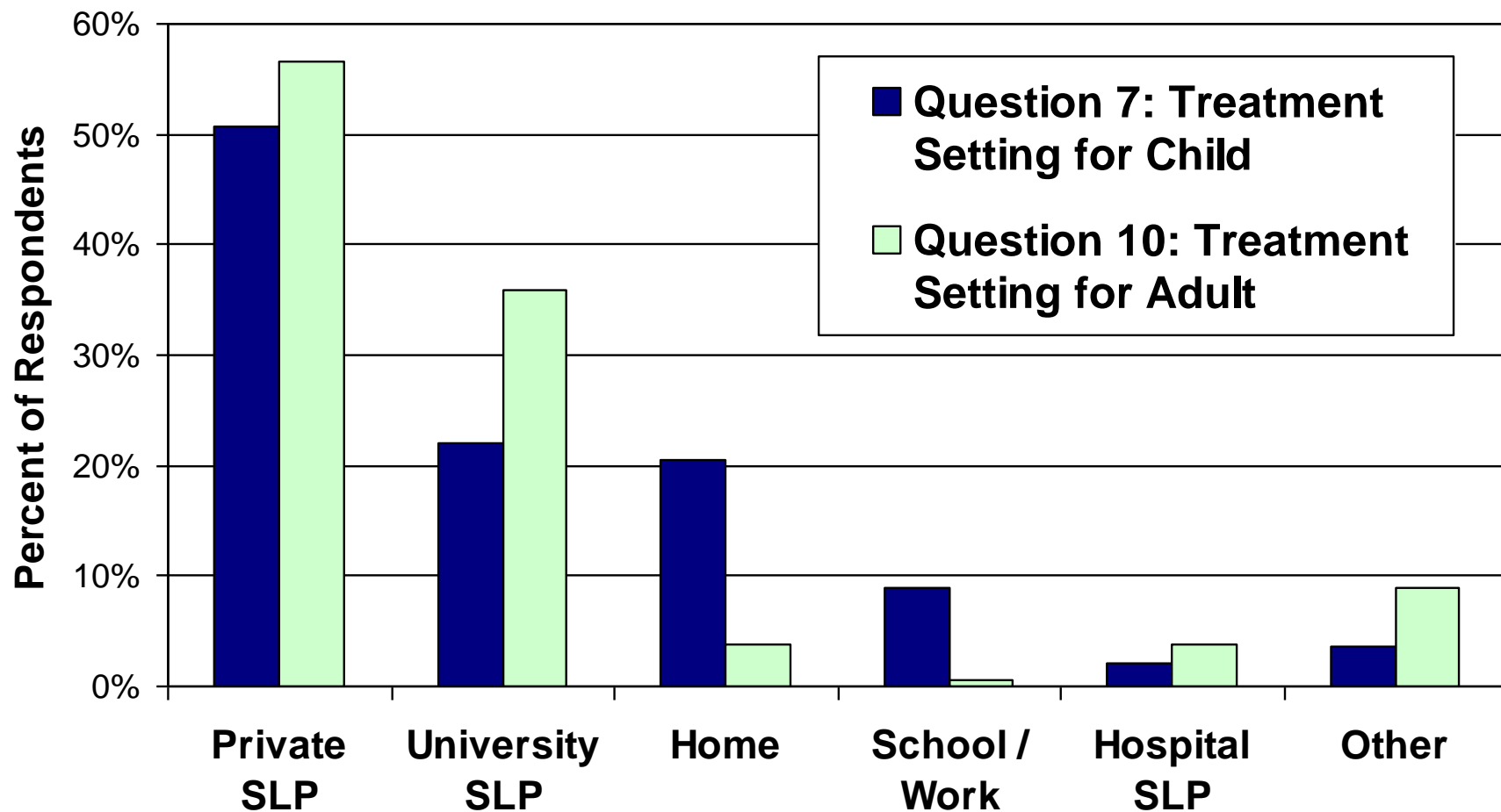
Questions 5 and 6



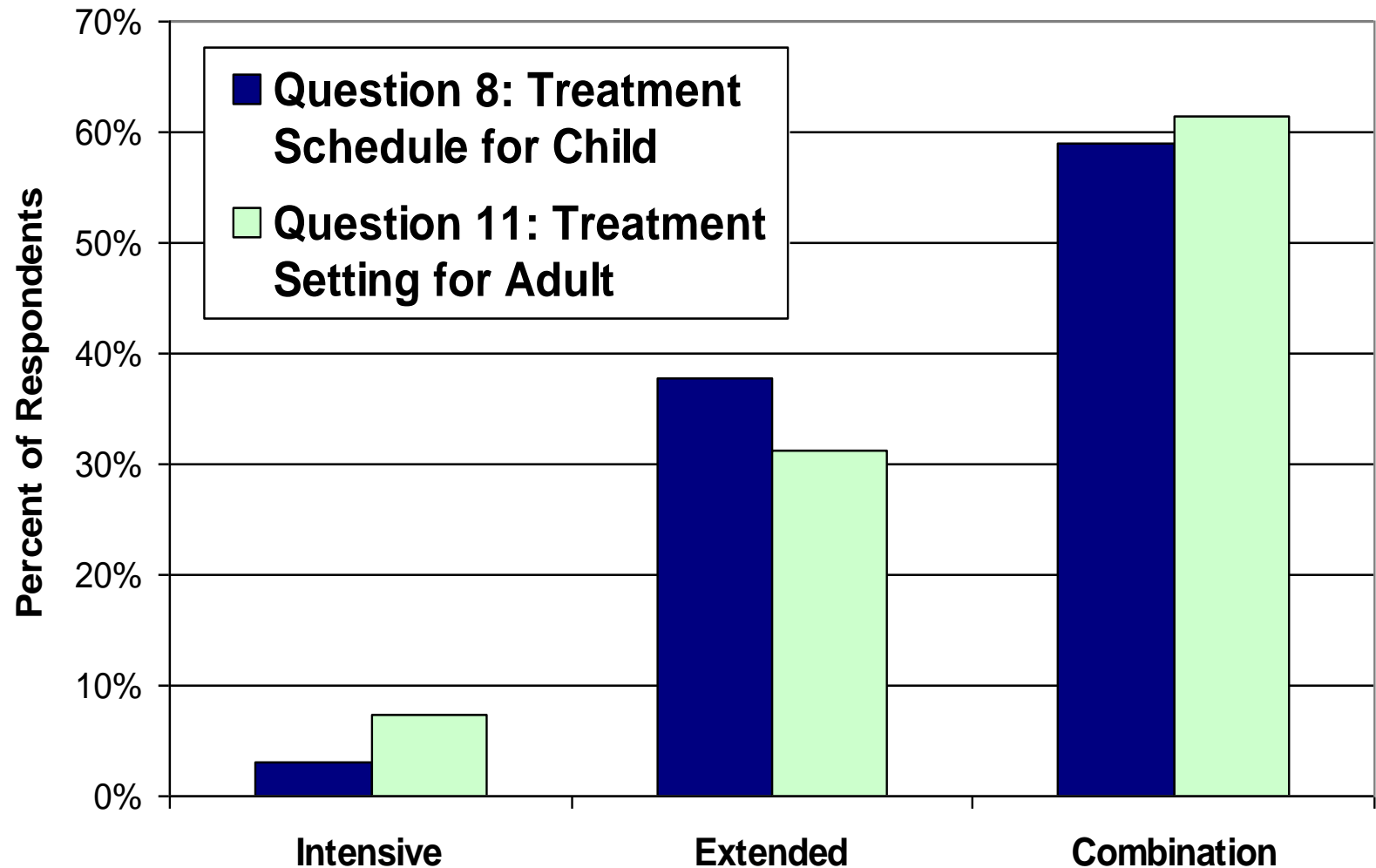
Opinions re Treatment & Resources

- **Q7:** What is the best *setting* for treating children who stutter? (Check only one.)
- **Q8:** What is the best *schedule* of therapy for children who stutter? (Check only one.)
- **Q9:** What are the best *goal(s)* of therapy for children who stutter? (Check all that apply.)
 - **Q10, Q11, Q12** repeated these Qs for **adults**
- **Q13:** Rate the *value* of resources for people who stutter: (1 = very low, 7 = very high.)

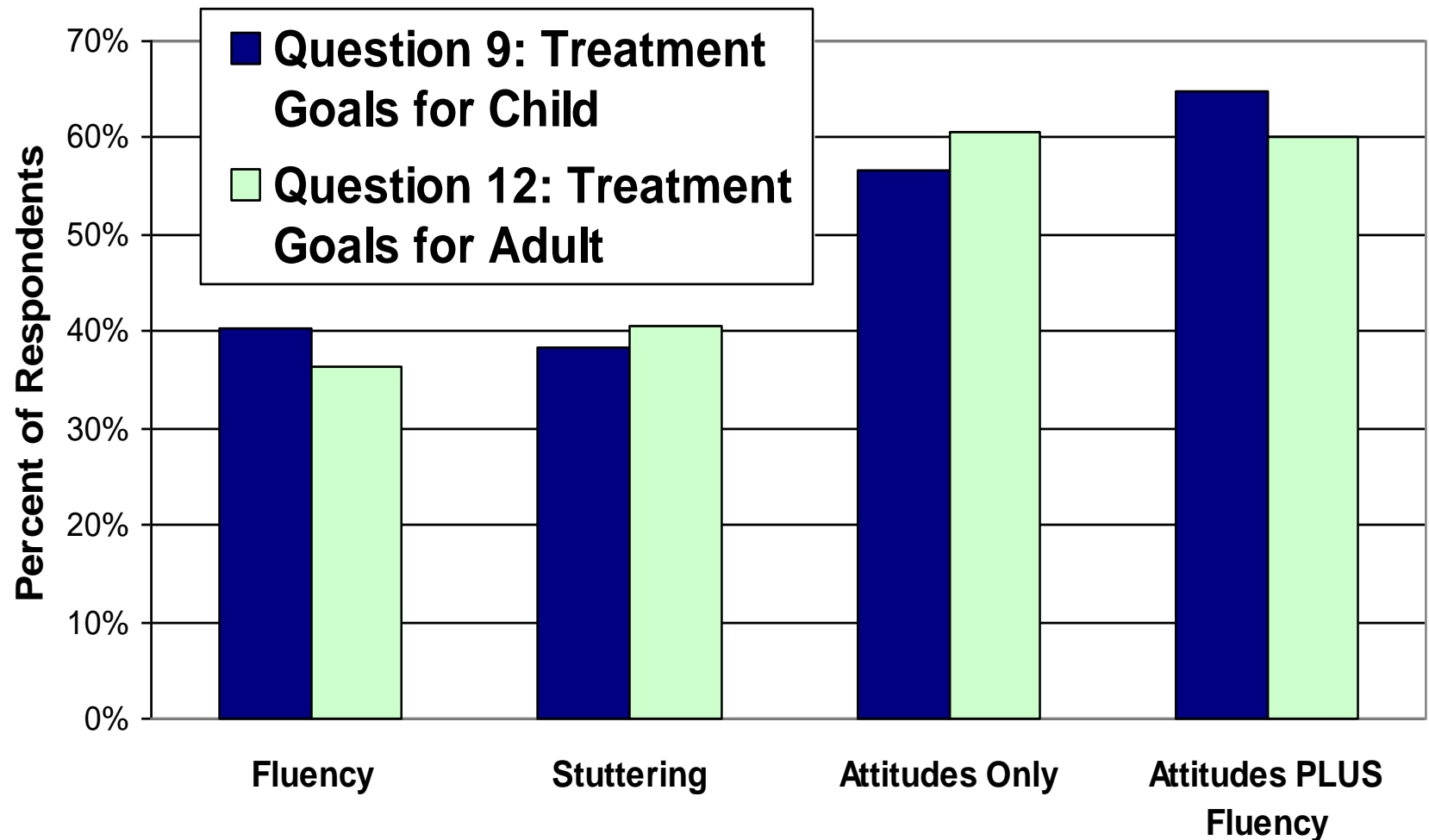
Questions 7 (children) & 10 (adults)



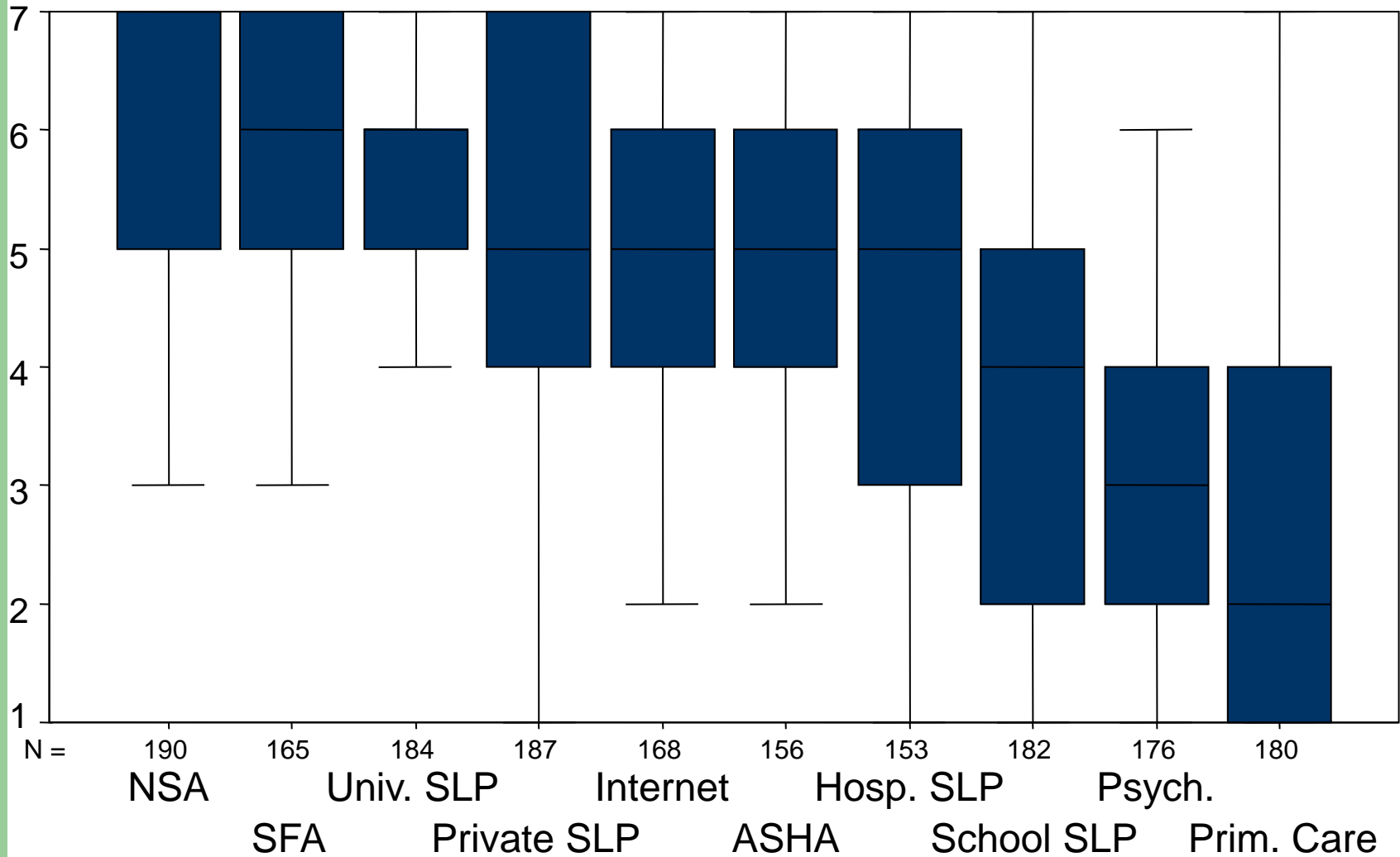
Questions 8 (children) & 11 (adults)



Questions 9 (children) & 12 (adults)



Question 13: Opinions re Resources



Discussion

- Findings from this study provide information about the opinions of NSA members regarding issues of importance to SLPs
 - Of course, not all members of a support group hold the same opinions; however, there was remarkable consistency across respondents
- Not surprisingly, these respondents rated the NSA very **highly** as an information source and resource for people who stutter

Opinions about SLPs

- Respondents generally held a higher opinion of SLPs at universities and in private practice than SLPs in schools or hospitals
- This finding should be of significant concern
 - Many people may not have access to private clinicians because of insurance limitations
 - Many children who stutter may only have access to treatment in school settings
 - *Many may have to seek therapy in settings they do not prefer and in which they have less confidence*

Opinions about PCPs

- Respondents also expressed concerns about primary care **physicians** as a source of information about stuttering
 - This may be associated with the fact that many physicians advise parents to “wait and see” whether their children will outgrow stuttering
 - Of course, there is considerable controversy about this issue among stuttering specialists, too
- *Will this situation improve when physicians receive more accurate info from SFA and NSA?*

Opinions about ASHA

- Many respondents did **not** view ASHA to be a resources they would consider for information about stuttering
 - Although there are certainly other resources available (e.g., SFA, NSA), it would seem appropriate for ASHA to further its attempts to reach out to people who stutter
 - Note that the Special Interest Division (DIV-4) *has* done this, e.g., with invitations to NSA members to participate in leadership conferences

Opinions about Early Intervention

- Respondents appeared to have some misconceptions about accepted early intervention practices
 - More than 20% said they would wait and see if their child would outgrow stuttering, *even though research suggests that children of people who stutter may be at greater risk for continuing*
 - Many respondents also indicated that they would contact a psychologist or PCP, even though these resources were rated lower overall

Opinions about Treatment

- Respondents expressed a strong preference for treatment that addresses not only speech fluency, but also their **feelings** about speech
 - This is consistent with research indicating that people who stutter value treatment aimed at improving their communication attitudes (e.g., Yaruss et al., 2001)
- Less than 10% thought school therapy was best for children, though this is a primary setting for therapy!
- Most thought in-clinic therapy was best for adults, though many have expressed frustration about difficulties transferring skills out of the clinic!

Conclusion: SLPs & support groups

- Because people who participate in support groups come into contact with many other people who stutter, it is important for support group members to be **well-educated** about stuttering and stuttering treatment options
- SLPs should partner with support groups to provide this education and to **advocate** for early intervention and appropriate treatment within the community of people who stutter.

FOR MORE INFORMATION...

- Send an email to

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- Or...give us your email address and we will send you a PDF version of this poster.

ALSO...

- Don't forget to visit the NSA booth to see the new materials, including our new guide for parents:

