

Communication Disorders and Stigmas

A study commissioned by the American Speech-Language-Hearing Association

May 2024





Objectives & Methodology

Research Objectives:

This survey aims to profile the stigmas experienced by American adults (ages 18+) with communication disorders.

Research objectives include determining...

- Impact of hearing and/or speech-language difficulties or differences on personal life, work/school, and interpersonal relationships.
- Attitudes toward difficulties.
- Others' perceptions toward people with difficulties, and the stigmas that persist in life.
- What could improve daily life for people with hearing and/or speech-language difficulties.
- Understanding attitudes toward—and experiences with—treatment.

Methodology:

Method: 10-minute online survey

Sample size: n=1,004 Adults 18+ with hearing and/or speech-language

difficulties

Fieldwork: February 21 – 26, 2024

- A census-clicks approach to sampling and weighting was used. This
 methodology is often used to ensure a representative sample of hard-toreach groups and involves sampling and weighting to the closest known
 population; in this case US adults ages 18+.
- Unless otherwise specified, data is presented on total (hearing and/or speech-language difficulties).
- Subgroups:
 - Have only hearing difficulties (n=784)
 - Have only speech-language difficulties (n=153)
 - Have both hearing and speech-language difficulties (n=67)





Key Findings: Impact of Hearing, Speech or Language Difficulties

Many people experienced stigmas, as well as feelings of inadequacy and isolation. Sixty-five percent reported they experienced at least one of the following forms of stigma at least sometimes: feeling like an outcast, feeling less than, feeling judged, being seen as less intelligent, not having achievements recognized, being labeled, being bullied or being talked down to.

• Those with speech-language difficulties were more likely to report they experienced stigmas – 88% vs. 58%.

A vast majority of adults with hearing and/or speech-language difficulties (83%) indicated that their communication difficulties have impacted their lives, and nearly half (49%) stated that important relationships have been affected.

• The impact varied among those with hearing difficulties vs. speech-language difficulties, with individuals experiencing speech-language difficulties reporting greater effects on their lives and relationships.

These difficulties caused increased stress and frustration for nearly one-third (31%) and stress and anxiety related to communication difficulties (28%). Outside of important relationships, nearly 60% are stressed during social gatherings or events, and an equivalent number wished other people were more willing to accommodate individuals with difficulties.

• Those with speech-language difficulties more commonly reported negative effects, compared to those with hearing difficulties.



Key Findings: Impact of Hearing, Speech or Language Difficulties *(Continued)*

Nearly three-quarters indicated that they are able to communicate effectively – and more than 4-in-10 didn't view their issues as something that needed to be "fixed." A similar number also indicated that they had become more empathetic and kind as a result of their difficulties.

When asked what could improve living with their hearing and/or speech-language difficulties, the top items were (each reported by about 3-in-10):

- Being given adequate time to communicate
- More knowledge of communication tips among the general public
- People not making assumptions about them based on their difficulties

Additionally, having more information on treatment options may prove beneficial, as about half say they did not have enough information about treatment.

 Those with speech-language difficulties more commonly report that many of the strategies listed could help improve their lives, and they also reported a larger gap in information around treatment.

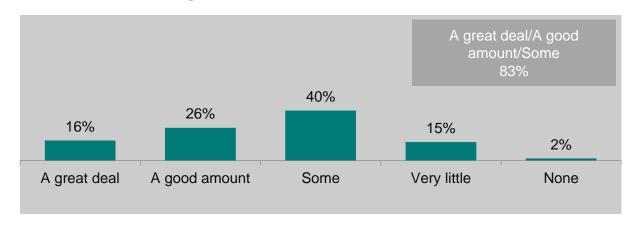


Impact of Hearing and/or Speech-Language Difficulties

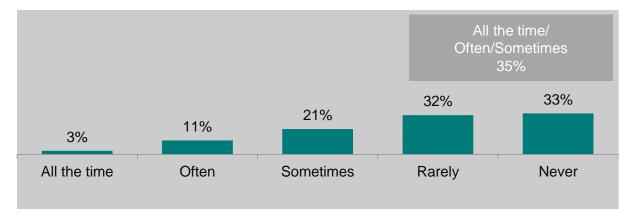
More than 8-in-10 acknowledged the impact of their hearing or speech-language difficulties on their lives, and over a third (35%) have faced discrimination due to communication challenges.



Impact of Difficulties on Life



Frequency of Discrimination Due to Difficulties

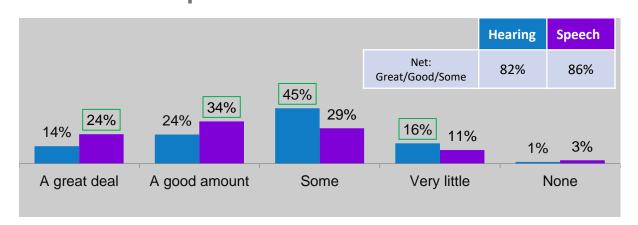




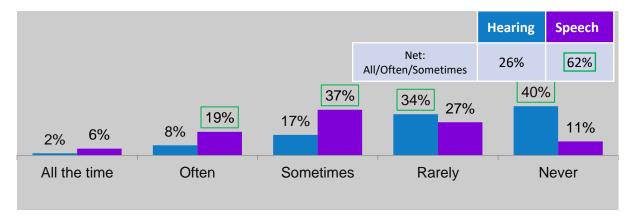
A large majority (80%+) of both groups indicated that communication difficulties have had some level of impact on their lives. However, individuals with speech-language difficulties reported experiencing greater effects compared to their counterparts with hearing difficulties. Additionally, those with speech-language difficulties alone reported more instances of discrimination.



Impact of Difficulties on Life



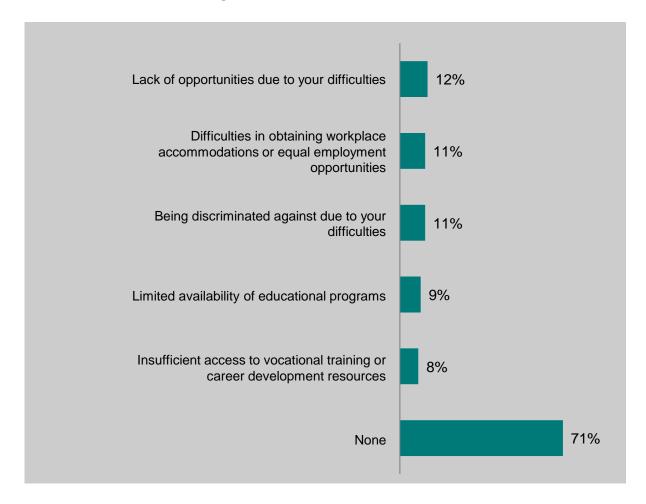
Frequency of Discrimination Due to Difficulties



When considering the impact on school or work, those with hearing or speech-language difficulties highlighted a lack of opportunity, challenges in obtaining workplace accommodations, and facing general discrimination as the top challenges.



Impact on School/Work

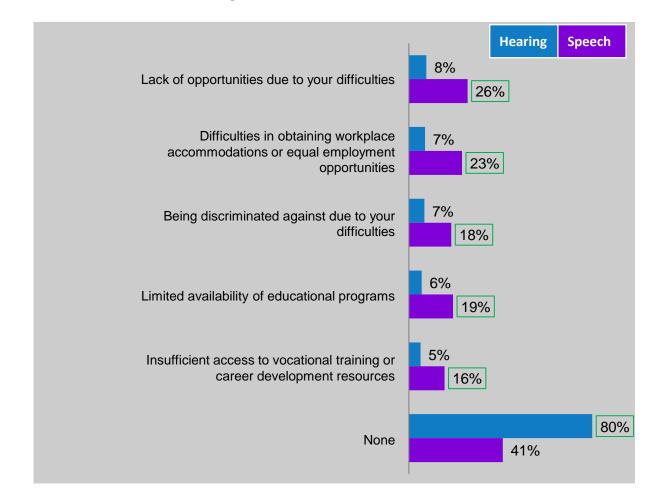




Individuals with speech-language difficulties reported experiencing more issues at school or work compared to their counterparts with hearing difficulties. Notably, more than a quarter (26%) of those with speech-language difficulties alone felt that there are limited opportunities available to them due to their communication challenges.



Impact on School/Work

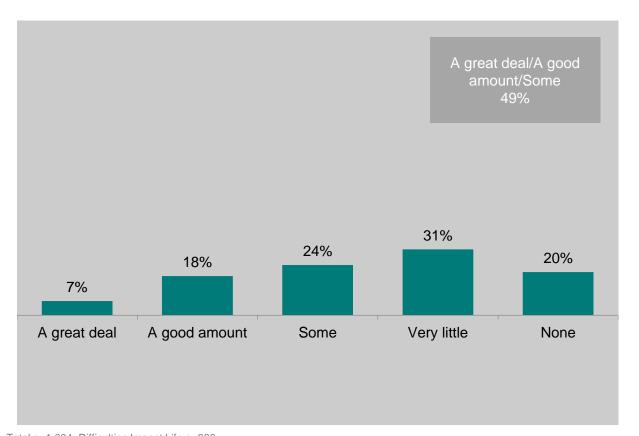


Nearly half stated their hearing or speech-language difficulties have impacted important relationships in their lives.

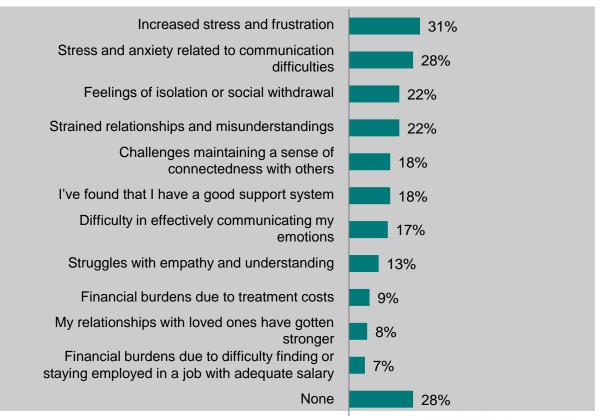


The primary effects included increased overall stress and frustration, as well as stress and anxiety related to communication difficulties. Additionally, individuals reported dealing with feelings of isolation, social withdrawal, and strained relationships.

Impact of Difficulties on Important Relationships



How Life Has Been Affected

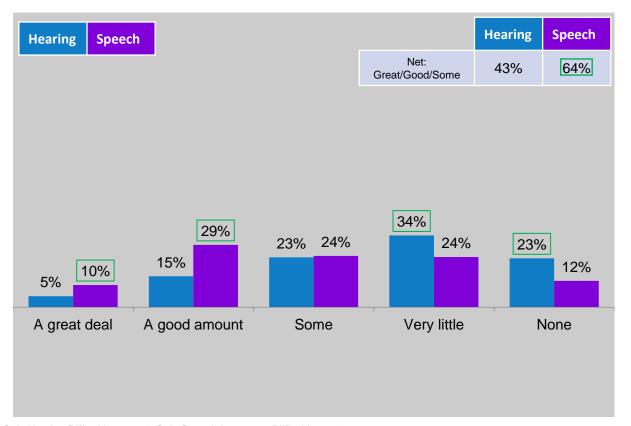




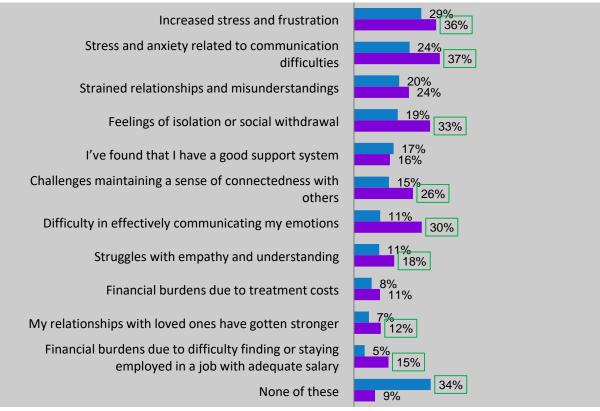
Those with speech-language difficulties were more likely to indicate that their difficulties have had at least some impact on important relationships compared to those with hearing difficulties (64% vs. 43%). Additionally, those with speech-language difficulties more frequently reported experiencing each of the areas listed.



Impact of Difficulties on Important Relationships



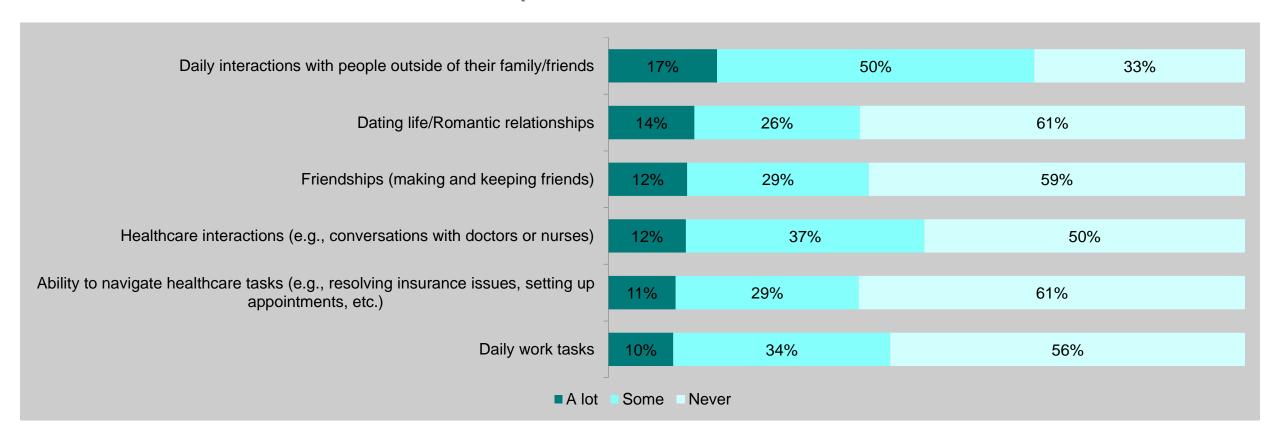
How Life Has Been Affected



Daily interactions with people outside of their family and friends was the area most affected by hearing and speech-language difficulties, with two-thirds (67%) stating at least some impact. Approximately half stated that their difficulties impacted their healthcare interactions and daily work tasks to at least some degree.



Impact of Difficulties on...



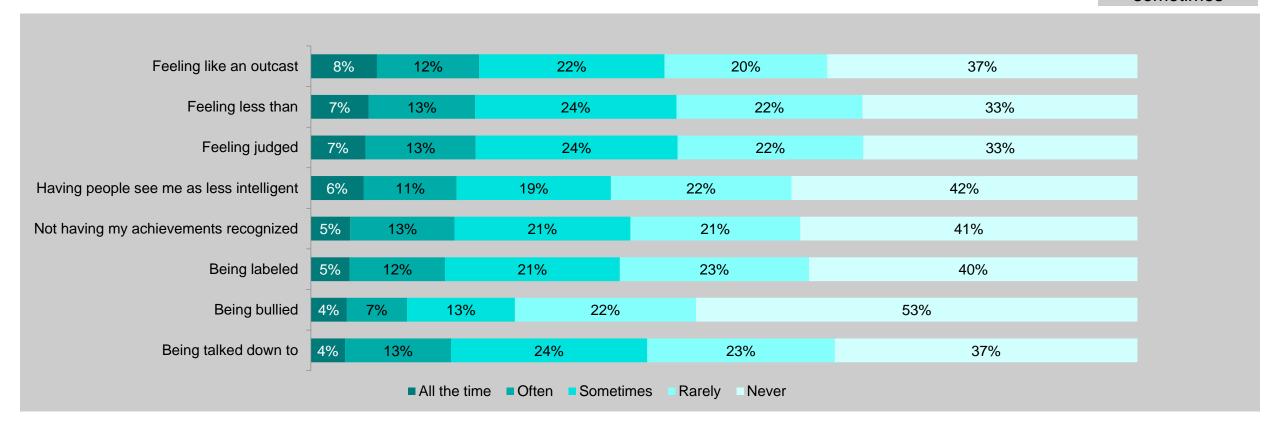


While individual occurrences of stigmatization were relatively low, nearly two-thirds (65%) experienced at least one form of stigma at least sometimes.



Frequency of Being Stigmatized Due to Difficulties

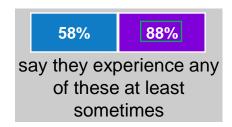
65% say they experience any of these at least sometimes

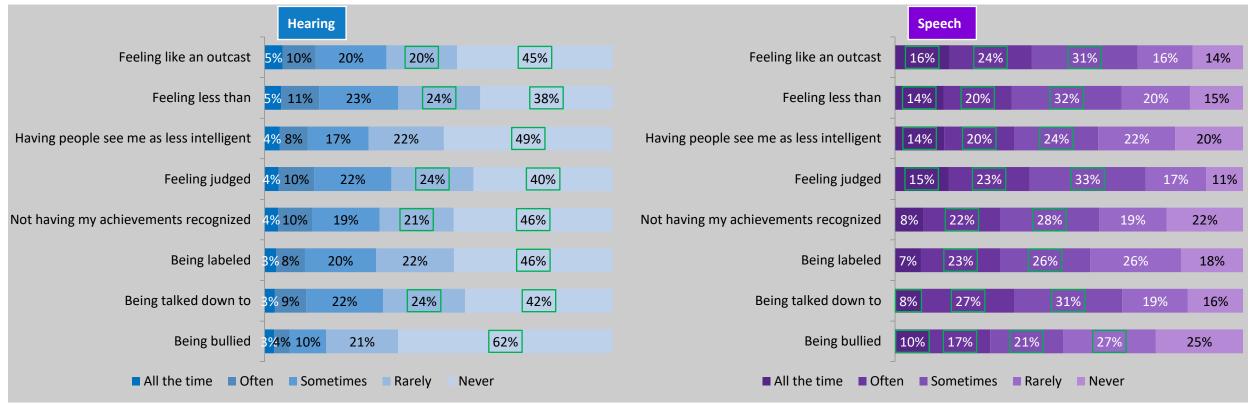


Though both groups experienced stigmas, the speech-language only group (88%) faced challenges far more frequently than the hearing only group (58%).



Frequency of Being Stigmatized Due to Difficulties





Nearly three-quarters (73%) stated they are able to communicate effectively, and more than half (58%) mentioned that people are generally understanding and patient. However, nearly 60% expressed feeling stressed in social gatherings and wished people were more willing to accommodate individuals with difficulties.



Feelings of inadequacy and isolation were each reported by 38%. Nearly 3-in-10 felt judged, and about a quarter said they are viewed as less capable or labeled.

Attitudes Regarding Difficulties (Strongly/Somewhat Agree)

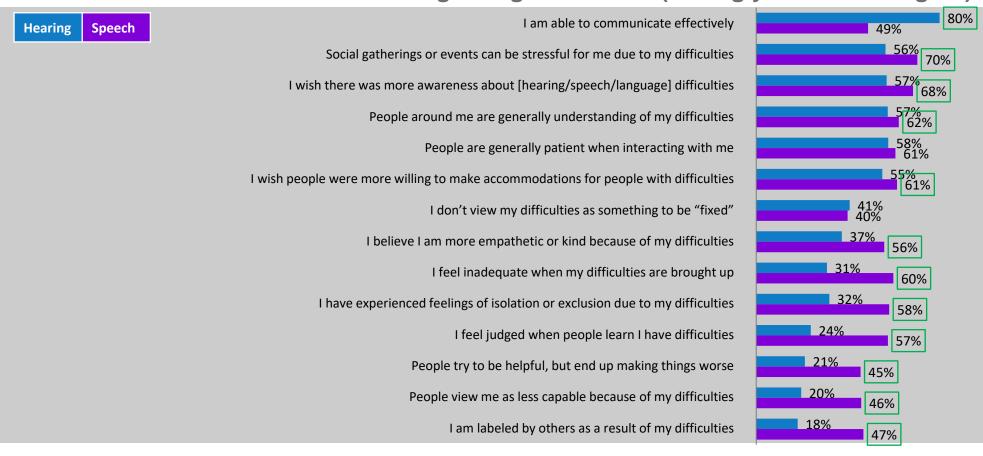




Both groups felt their difficulties were not something that needed to be "fixed" and that people were generally patient with them. Those in the hearing only group were more likely to indicate they could communicate effectively (80%) compared to those in the speech-language only group (49%). Speech-language only individuals were more likely to agree with many statements around the negative effects of their difficulties.



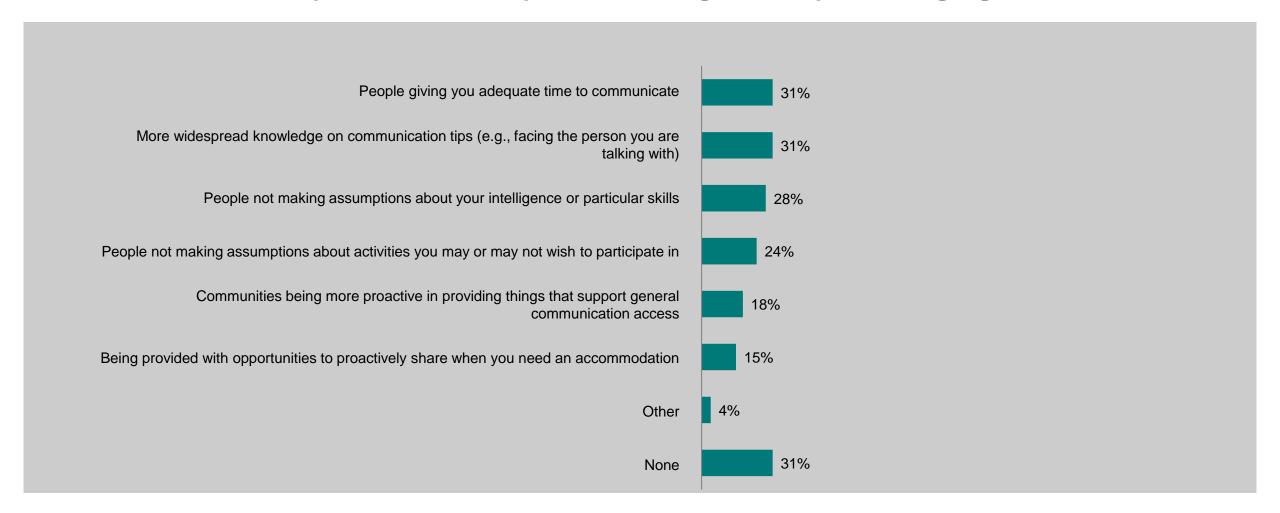
Attitudes Regarding Difficulties (Strongly/Somewhat Agree)



The most desired improvements were to have adequate time to communicate, more widespread knowledge on communication tips, and people not making assumptions about intelligence or skills.



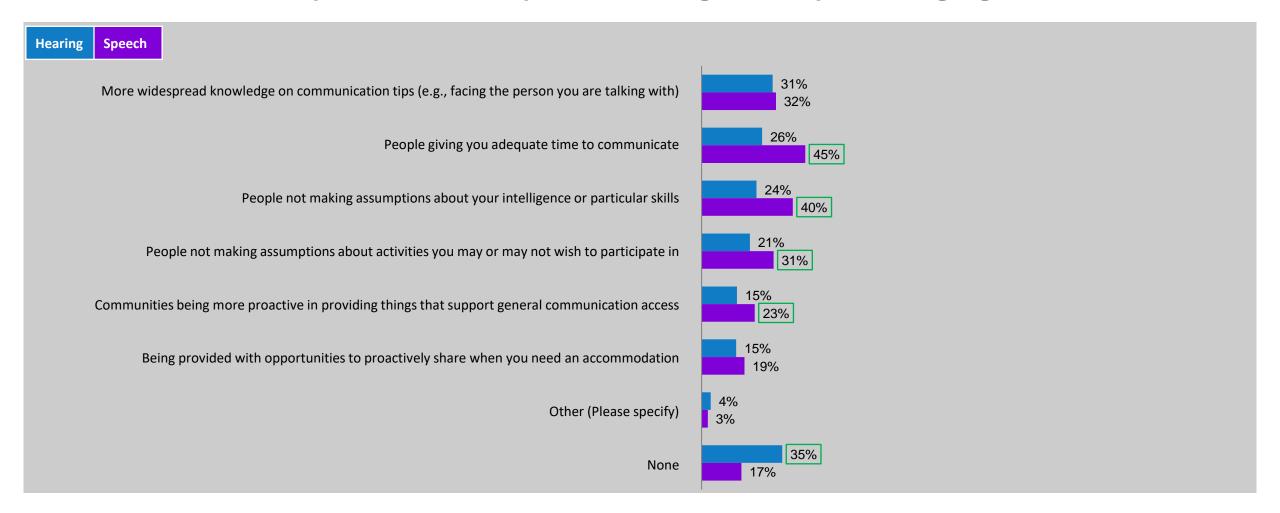
What Could Improve Life For People With Hearing and/or Speech-Language Difficulties



The speech-language only group was more likely to acknowledge that many of the suggested improvements could improve their lives as compared to the hearing only group.



What Could Improve Life For People With Hearing and/or Speech-Language Difficulties



Appendix: Hearing and/or Speech-Language Difficulties



Key Findings: Experiences With Communication Challenges

- Hearing difficulties were reported by more than 80% of individuals, while speech-language difficulties affected nearly a quarter. The most common diagnoses are hearing loss and tinnitus, with speech-language diagnoses being much less common. A quarter of individuals had not been diagnosed with any disorders related to their difficulties.
- Two-thirds of individuals with communication difficulties stated they have trouble hearing in a noisy environment, and about half have trouble understanding what others say. Other top challenges are difficulties following/engaging in conversations and distinguishing sounds.
- Nearly a fifth first noticed their difficulties when they were less than 18 years old, with the remainder emerging over time.
 Nearly half stated that their difficulties have gradually worsened over time, with about one-in-five indicating things have remained stable.
 - The hearing only group tended to have a later age of onset than the speech-language only group and were more likely to have stable
 or worsening symptoms.



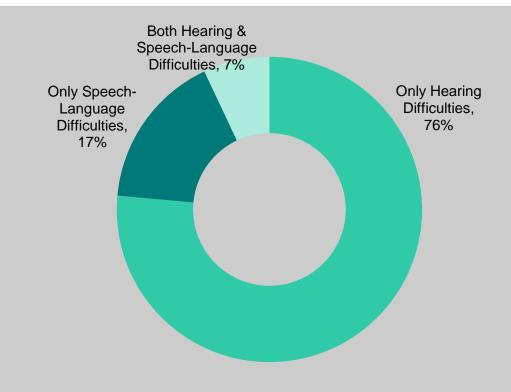
Key Findings: Experiences with Treatment

- 57% have previously received treatment, with 26% in total currently in treatment. The most common providers are audiologists and ENTs. Treatment timing varied widely.
 - Those in the hearing group were more likely to have sought treatment (58%) compared to those in the speech-language only group (52%). Treatment length and provider type varied across groups.
- More than one-third of those treated sought out treatment within 6 months of noticing difficulties. Anticipated cost, feeling
 the issue would resolve on its own, or not being sure where to seek treatment were the top reasons for delaying
 treatment.
 - The speech-language group was much more likely to seek treatment immediately vs. the hearing group (21% vs. 12%). Cost of
 treatment was the key inhibitor for the hearing group (41%), while for the speech-language group, feeling the issue would resolve on
 its own was the main reason for delaying treatment (38%).
- Overall, nearly two-thirds of respondents were satisfied with their treatment.
- For those who stopped treatment, key reasons were not thinking it was helping, or conversely, feeling that the problem had improved enough that treatment wasn't necessary.

Hearing difficulties were reported by more than 80% of individuals, while speech-language difficulties affected nearly a quarter.



TYPE OF DIFFICULTY

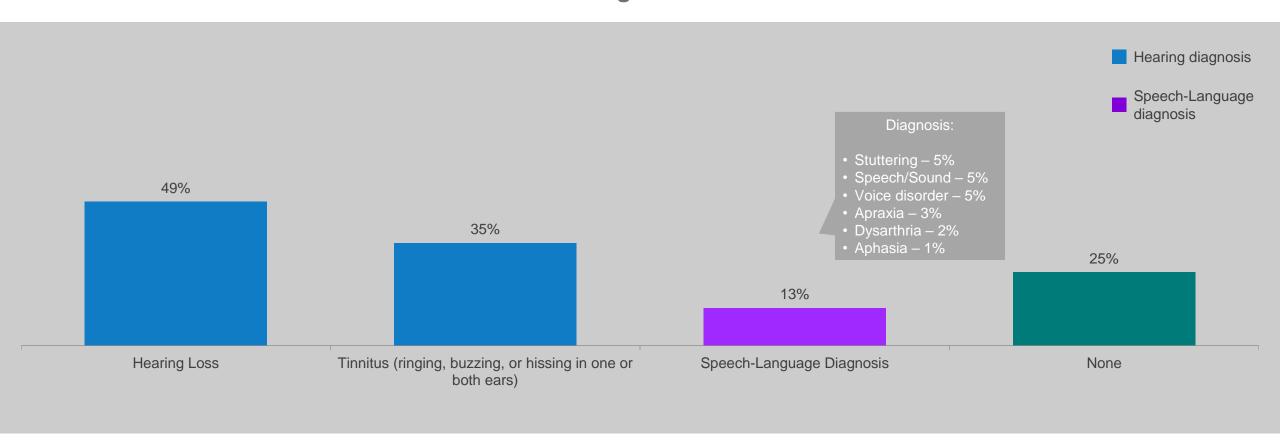




The most common diagnoses were hearing loss and tinnitus, with speech-language diagnoses being much less common. A quarter (25%) of individuals have not been diagnosed with any disorder.



Diagnoses

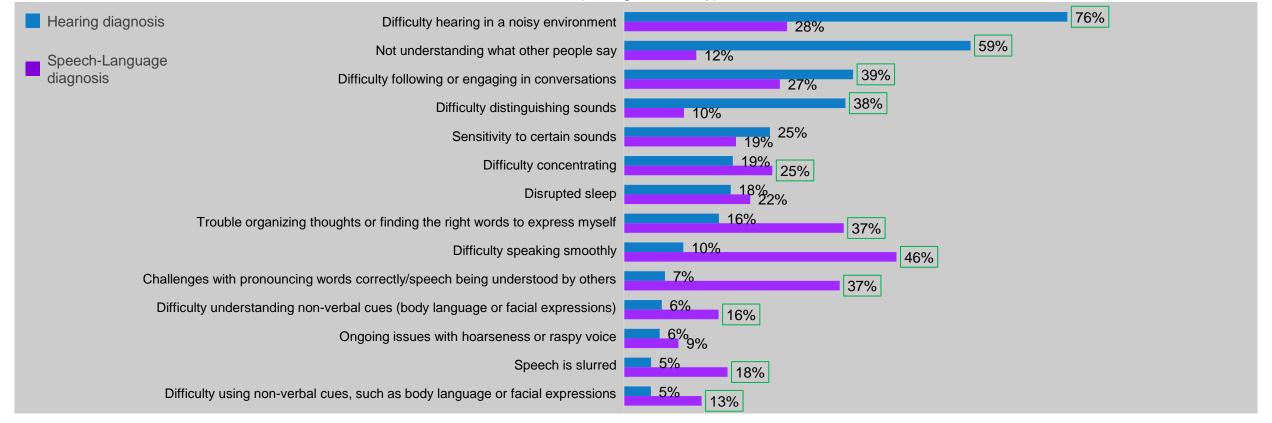


Difficulty hearing in a noisy environment was the most common symptom for those in the hearing alone group (76%). Alternatively, those with speech-language difficulties alone most commonly reported difficulty speaking smoothly (46%).



Symptoms Regularly Experienced

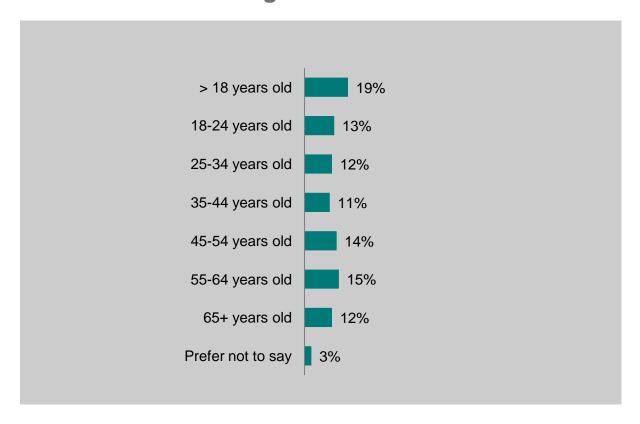
(Among Each Group)



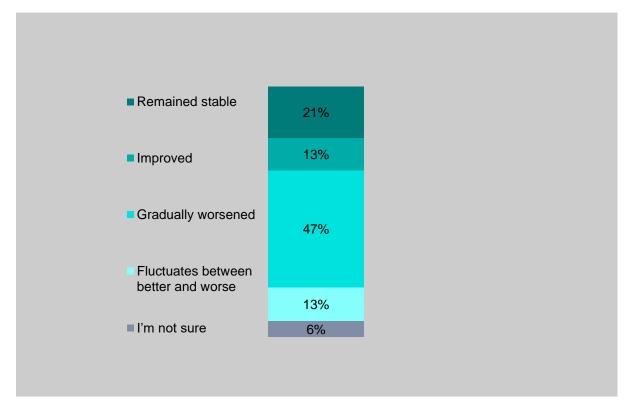
Nearly a fifth first noticed their difficulties when they were less than 18 years old, with the remainder emerging over time. Nearly half stated that their difficulties have gradually worsened over time, with about one-in-five indicating things have remained stable.



Age of Onset



Progression

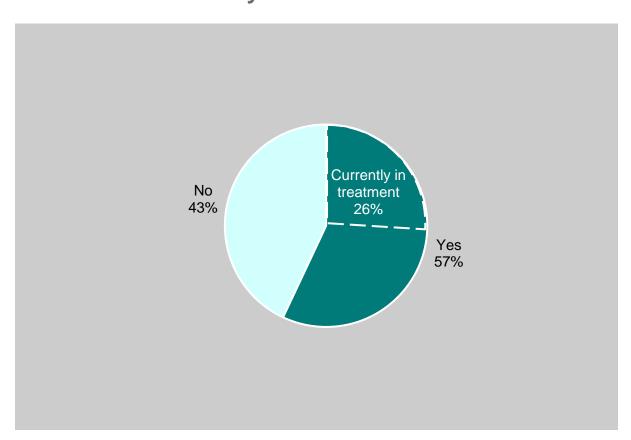




More than half (57%) have received treatment and 26% reported to be currently in treatment. The most common providers were audiologists and ENTs.

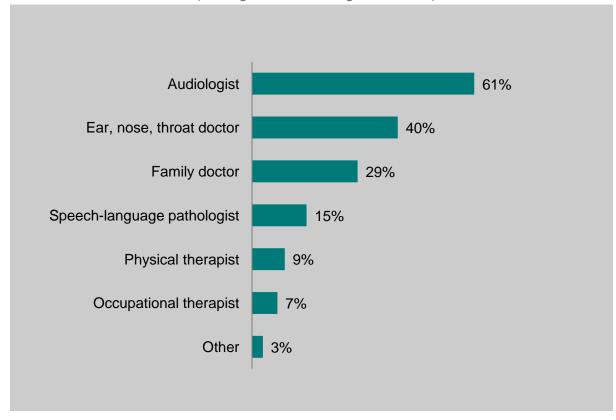


Previously Received Treatment



Treatment Providers

(Among those who sought treatment)

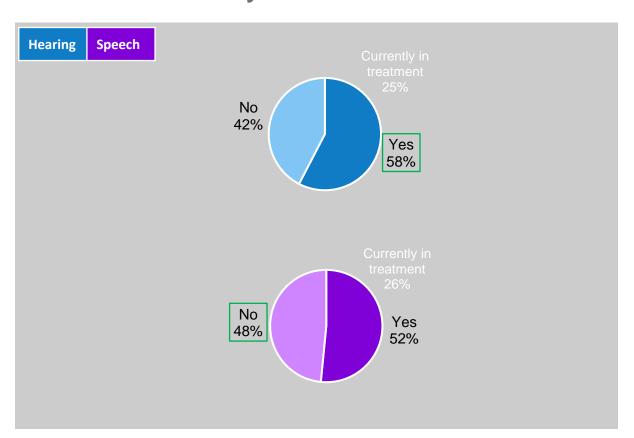




Those in the hearing group were more likely to have sought treatment (58%) compared to those in the speech-language only group (52%).

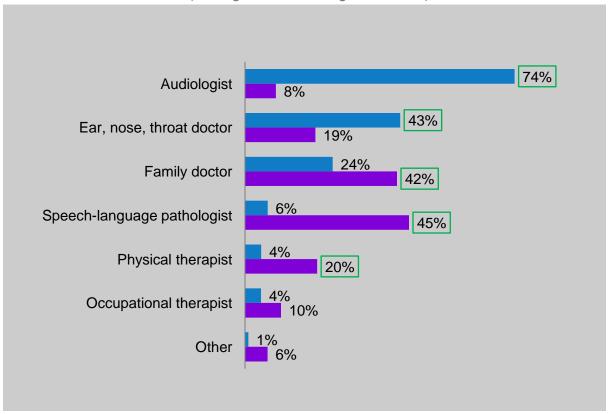


Previously Received Treatment



Treatment Providers

(Among those who sought treatment)



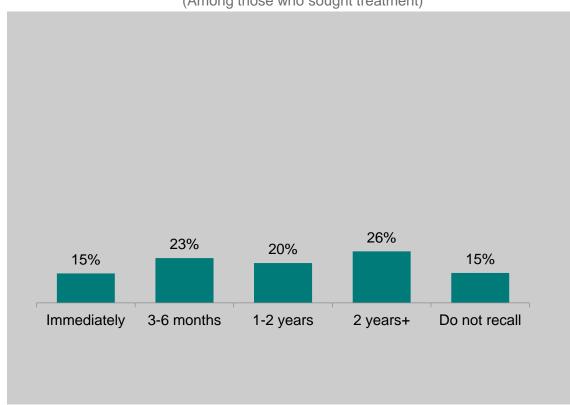
More than one-third of those treated sought out treatment within 6 months of noticing difficulties.



The anticipated cost, feeling the issue would resolve on its own, or not being sure where to seek treatment were the top reasons for delaying treatment.

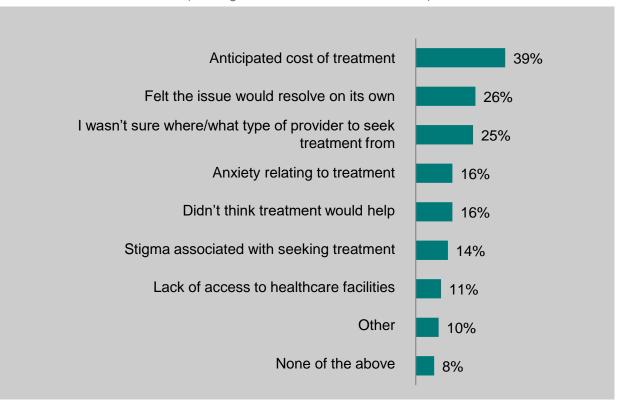
Time Before Seeking Treatment

(Among those who sought treatment)



Reasons for Delaying Treatment

(Among those who waited 3+ months)





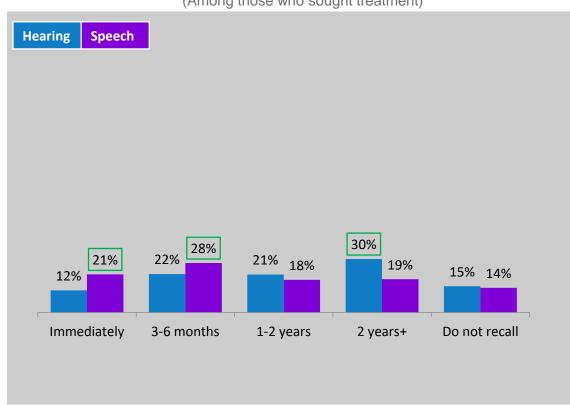
The speech-language group was much more likely to seek treatment immediately after noticing difficulty than the hearing only group (21% vs. 12%).



Cost of treatment was the key inhibitor for the hearing only group (41%), while for the speech-language group, feeling the issue would resolve on its own was the main reason for delaying treatment (38%).

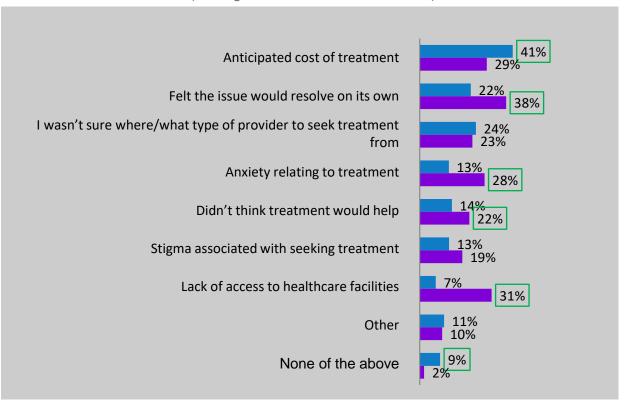
Time Before Seeking Treatment

(Among those who sought treatment)



Reasons for Delaying Treatment

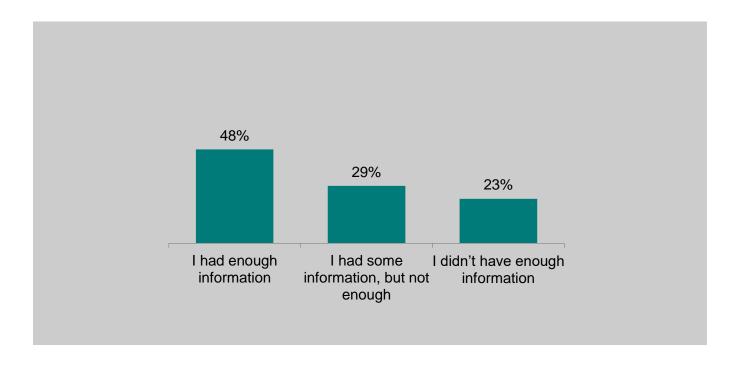
(Among those who waited 3+ months)



There were gaps in information availability, with just over half (52%) feeling they did not have enough information about treatment.



Information about Treatment

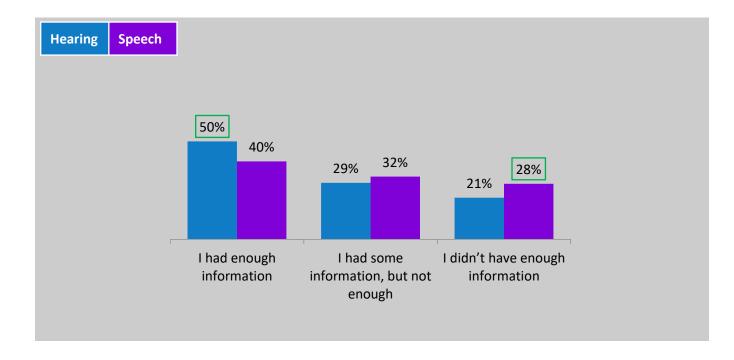




While information availability was an issue for both groups, it was a larger issue for the speech-language group: 60% indicate they did not have sufficient information about treatment options, compared to 50% of the hearing group.



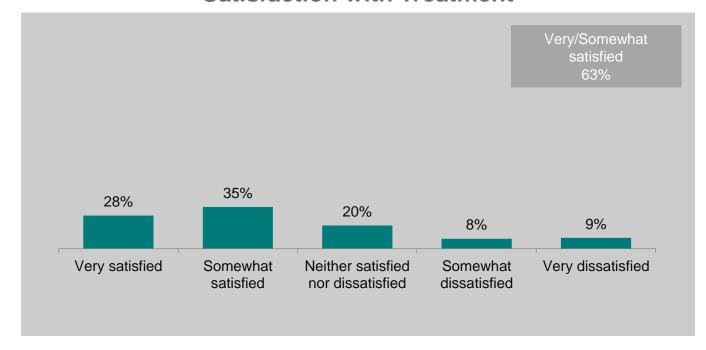
Information about Treatment



Overall, nearly two-thirds (63%) of individuals with difficulties were satisfied with their treatment.



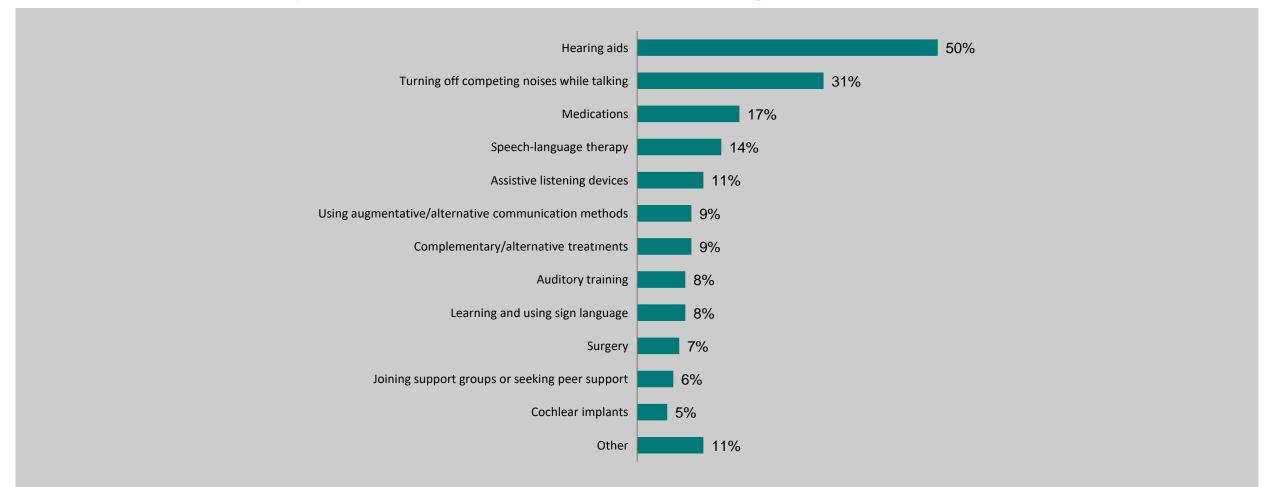
Satisfaction with Treatment



The most common treatments reported were hearing aids and reducing competing noise.

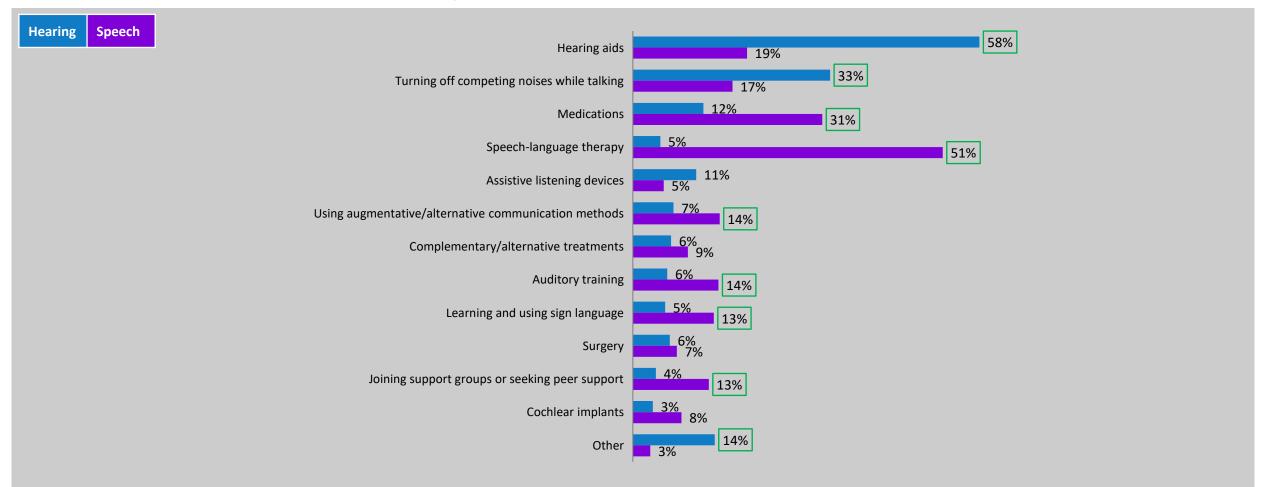


Types of Treatments/Interventions (Among Treatment Seekers)





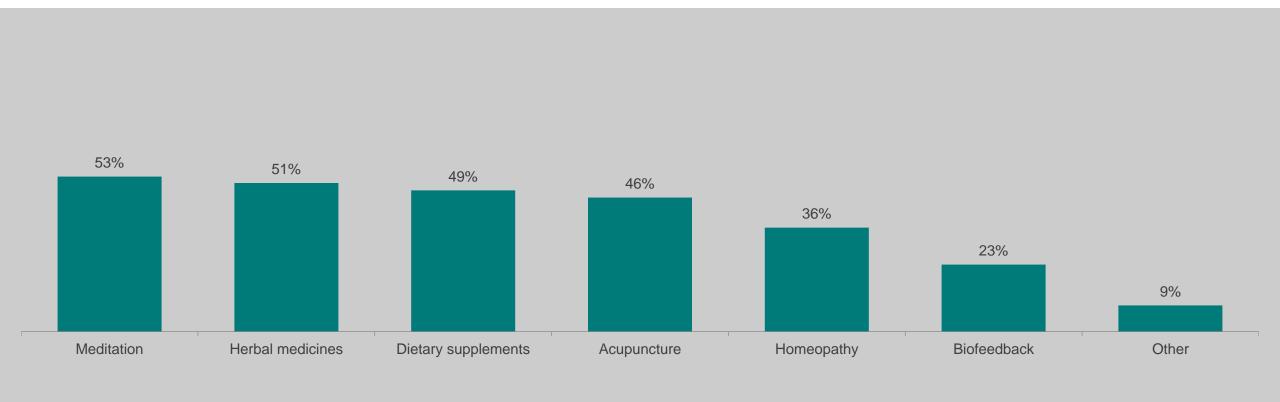
Types of Treatments/Interventions



While a small group, individuals that have tried complementary/alternative medicine for their difficulties tend to explore multiple methods. Among those that have used complementary/alternative approaches, about half have used meditation, herbal medicines, or dietary supplements, respectively. Acupuncture was another commonly used alternative.



Types of Complementary and/or Alternative Medicine Used/Received

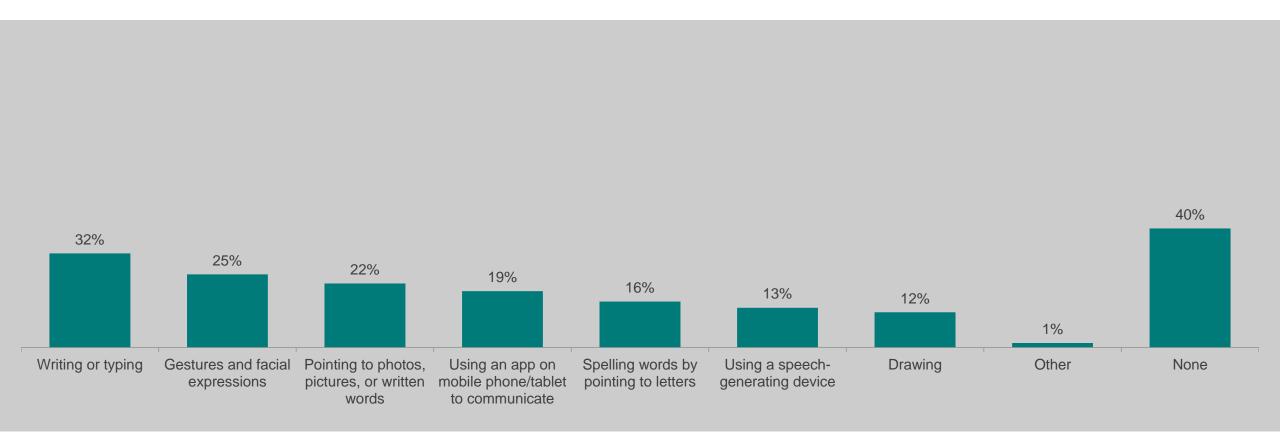




Among those with speech-language difficulties, about one-third used writing/typing as an alternative way of communicating. Other top methods were gestures and facial expressions, as well as pointing to photos, pictures, or written words.



Types of Augmentative/Alternative Communication Methods





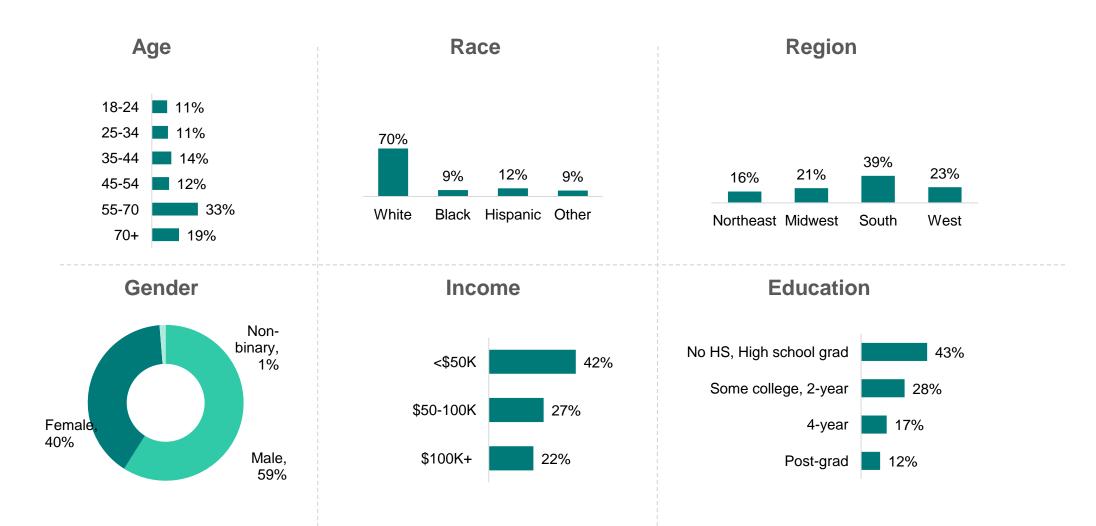
Appendix: General





Demographic Profile – Total Sample

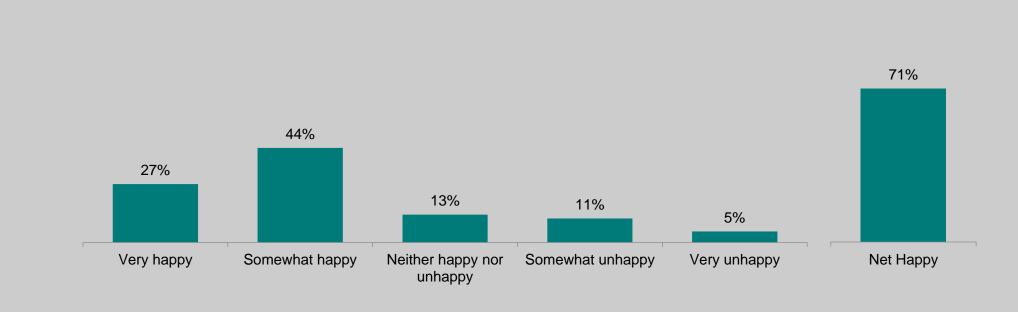
Total n=1,004



Despite the challenges that many people with hearing and/or speech-language difficulties face, they reported being generally happy.



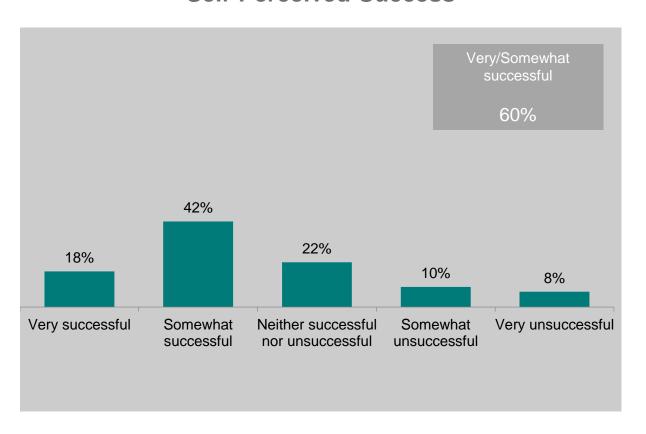
Overall Happiness



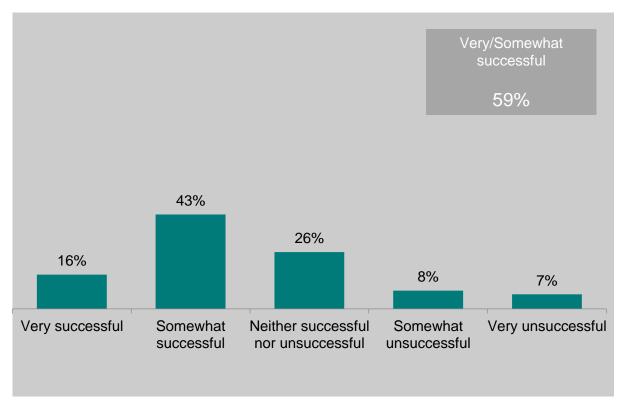
Six in ten individuals who have dealt with hearing and/or speech-language difficulties believe that they are successful, and a similar number believe others also perceive them as successful.



Self-Perceived Success



Perceived Success To Others

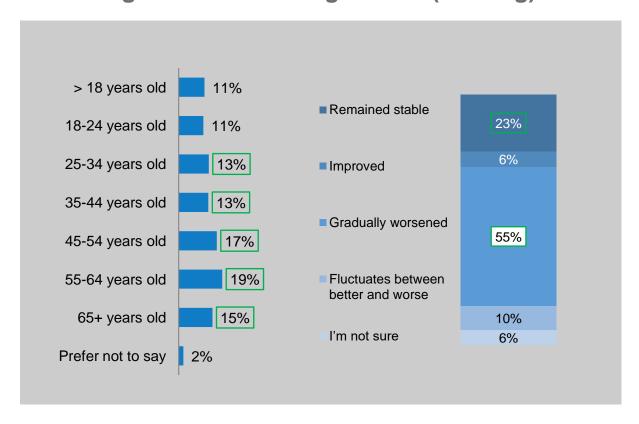




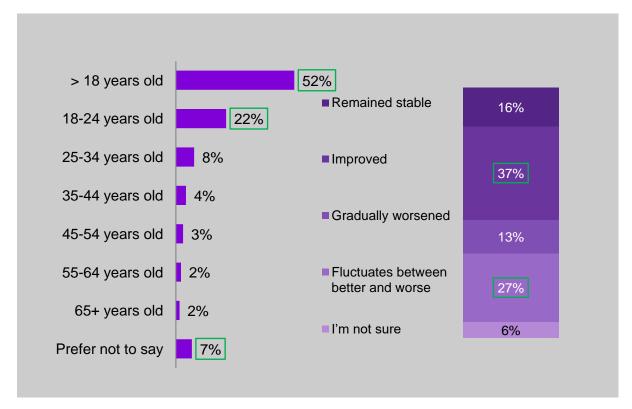
The hearing only group tended to have a later age of onset than the speech-language only group and was more likely to have stable or worsening symptoms. In comparison, the speech-language only group's age of onset was most commonly under 24, and more improvements were seen.



Age of Onset & Progression (Hearing)



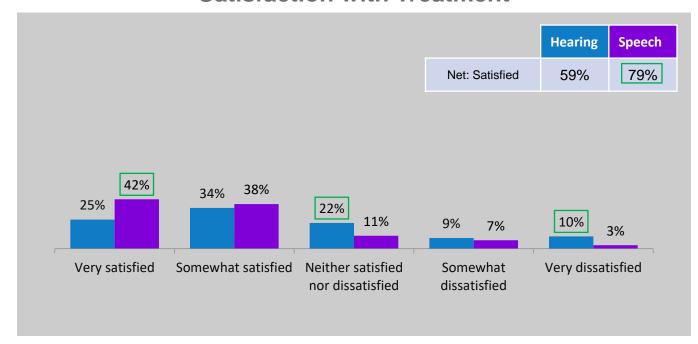
Age of Onset & Progression (Speech-Language)



Individuals in the speech-language only group were more satisfied with their treatment compared to their hearing only counterparts (79% vs. 59%).



Satisfaction with Treatment





Ways to Improve Interactions (Open End): Themes and Examples from Respondents

Communication: Slow down, speak clearly, face the listener

If they would only speak slower and a little louder and look me in my face, I could understand better. – Female, age 56

To slow down and speak clearly. To accept that they share some of the responsibility, i.e., if they want me to understand their message, they might have to adjust their delivery. – Female, age 69

Impact of environment

Wish they knew how noisy environments impact my hearing and communication. – Male, age 77

Recognition and legitimacy of hearing loss

That it's not a facade or something I can easily change. – Male, age 20 Even though you cannot see my disability, I do have problems. – Female, age 62 Every little bit of acknowledgment goes a long way. – Male, age 61





Ways to Improve Interactions (Open End): Themes and Examples from Respondents (Continued)

Patience

I wish people knew that, in moments when my speech or language difficulties become apparent, understanding and patience mean a lot. Taking the time to listen without making assumptions and fostering open communication can enhance our interactions and make them more inclusive. – Female, age 21

Frustration from others

I often experience anger from others for not being able to hear and understand them. I feel they believe I am being difficult on purpose. I wish people would not react with so much anger due to my hearing impairment. – Male, age 50

Misconceptions around intelligence and interest

Needing a statement repeated or a conversation clarified is not a sign of low intelligence or lack of interest. – Non-Binary, age 30

I wish people understood that I'm not stupid, I just have trouble hearing if more than one person is talking at the same time...I wish there was more information out there for them to understand that if I'm asking them to speak up, it's NOT because I'm not listening. – Female, age 53

Empathy

That at some point in their life, they may be impacted by hearing loss. – Male, age 65 I wish they could experience hearing difficulties for one entire day. Just one day. – Male, age 68

