



The Experience of People Who Stutter

A Survey by the National Stuttering Association

Executive Summary

The National Stuttering Association (NSA) conducted a survey in May 2009 to gather information about stuttering from the perspective of people who stutter: how stuttering affects their lives and their experience with stuttering treatment and support activities. 1,235 people responded to the survey, including 686 adults and 31 teens who stutter, 164 parents of children who stutter and 354 speech-language pathologists.

Key findings:

Stuttering interferes with work, school and family life. Children and adults who stutter often avoid speaking situations, feel embarrassed when people find out they stutter, and do not discuss their stuttering with family, friends and co-workers.

Eight out of 10 children who stutter have been bullied or teased. 40% of adults have been denied a job or promotion because of their stuttering.

While there is no cure for stuttering, speech therapy helps the majority of children and adults who stutter.

- Therapies that change attitudes toward speaking and stuttering were considered more successful than therapies that focus on speech mechanics.
- People who had speech therapy from a Board Recognized Specialist in Fluency Disorders had a more successful therapy experience than those who did not.
- Overall, however, 84% experienced a relapse after improving their fluency in therapy.

Stuttering support makes a difference. People who participate in the NSA's local chapters or national conference report fewer negative effects of stuttering and more successful speech therapy than those who do not. Support groups help people improve their self-confidence and develop positive attitudes about speaking and stuttering.

Alternative treatments for stuttering, such as psychological counseling, prescription medication and assistive devices were generally less successful than speech therapy in helping people manage their stuttering.

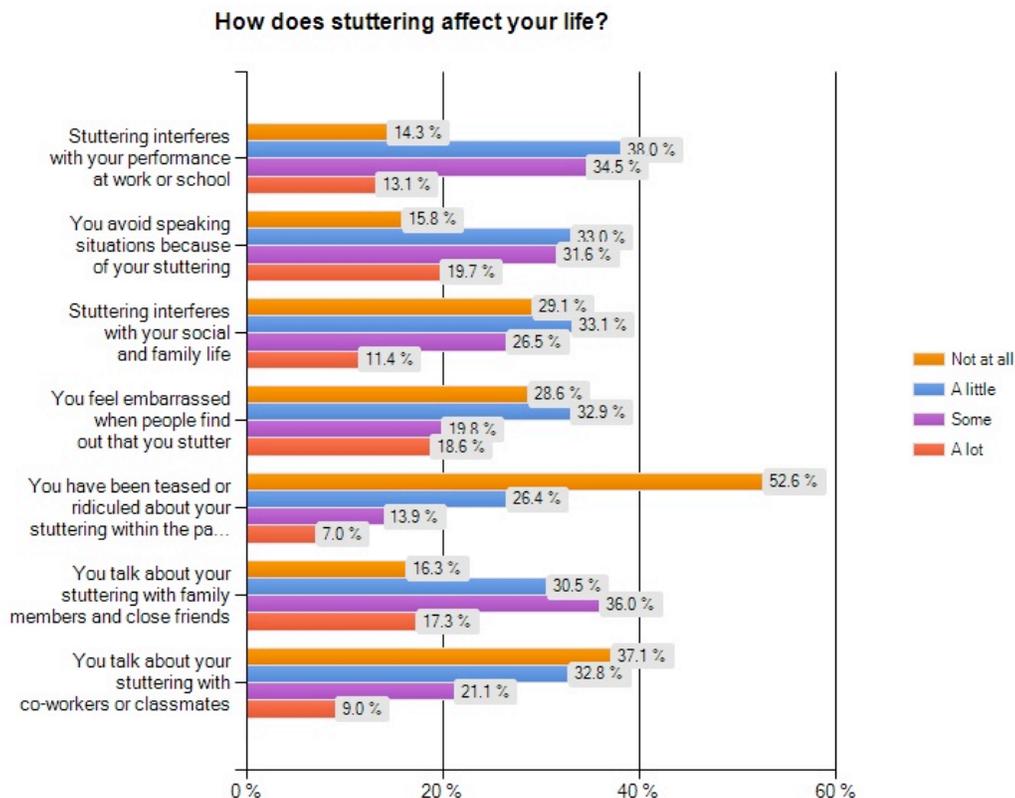
Although most experts agree that early therapy helps preschool children overcome stuttering, 30% of parents were advised by a pediatrician or speech therapist to defer speech therapy until the child was older.

14% of parents say their children have been denied speech therapy in school.

Adults who stutter

Life impact of stuttering

Stuttering is more than disfluent speech: It has an emotional and social impact as well. Unlike most other disorders, stuttering often is a source of shame and embarrassment that prompts stutterers to avoid speaking situations and refrain from discussing their stuttering. Four out of 10 respondents say they have been denied a job, promotion or school opportunity because of their stuttering.



Stuttering support activities can help people come to terms with stuttering

Stuttering support activities such as the National Stuttering Association's local support groups and national conference help people build their self-confidence and deal with the emotional side of stuttering.

The survey found a significant difference in the life impact of stuttering on adults who are active participants in the NSA: They are less likely to avoid speaking situations and less likely to say their stuttering interferes with work or school. They also are more likely to talk about stuttering with family members, friends and co-workers.

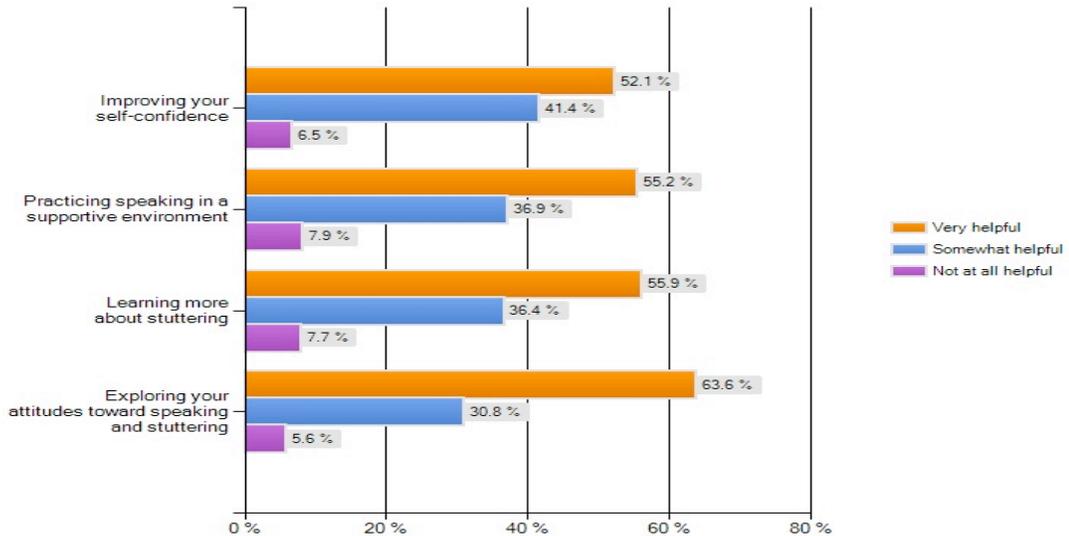
Since all respondents to the survey had some connection to the NSA – as a paid member, participant, former member/participant or web site registrant – we compared *those who were active participants in the last three years* to those who were not. The NSA made the same comparison in a 2002 survey of paid members and found comparable significant differences between active participants and inactive members.

Participated in adult chapters in the last 3 years		YES	NO
Stuttering interferes with your performance at work or school	Not at all	15.2%	12.7%
	A lot	10	13.3
You avoid speaking situations because of stuttering	Not at all	17.8	14.2
	A lot	12.3	24.6
You feel embarrassed when people find out that you stutter	Not at all	36.5	21.7
	A lot	10.6	24.6
You talk about your stuttering with family and close friends	Not at all	13.8	19
	A lot	19.9	12.7
You talk about your stuttering with co-workers or classmates	Not at all	29.2	44.4
	A lot	12.9	5.7

Attended a NSA conference in the last 3 years		YES	NO
Stuttering interferes with your performance at work or school	Not at all	17.8%%	11.6%
	A lot	8.3	13.1
You avoid speaking situations because of stuttering	Not at all	21.2	13
	A lot	12	22
You feel embarrassed when people find out that you stutter	Not at all	34.8	24.7
	A lot	11	21.9
You talk about your stuttering with co-workers or classmates	Not at all	24.4	42.2
	A lot	15.6	6

71% of respondents have attended stuttering support groups (including local support groups and therapy continuation groups led by speech therapists) and about half currently attend local NSA chapters. The majority of those who have attended NSA chapters or the NSA national conference say the experience has been very helpful in improving their self-confidence, practicing speaking, learning more about stuttering and exploring attitudes toward speaking and stuttering. Nearly all would recommend support groups to others.

How helpful was your experience in a stuttering group in:



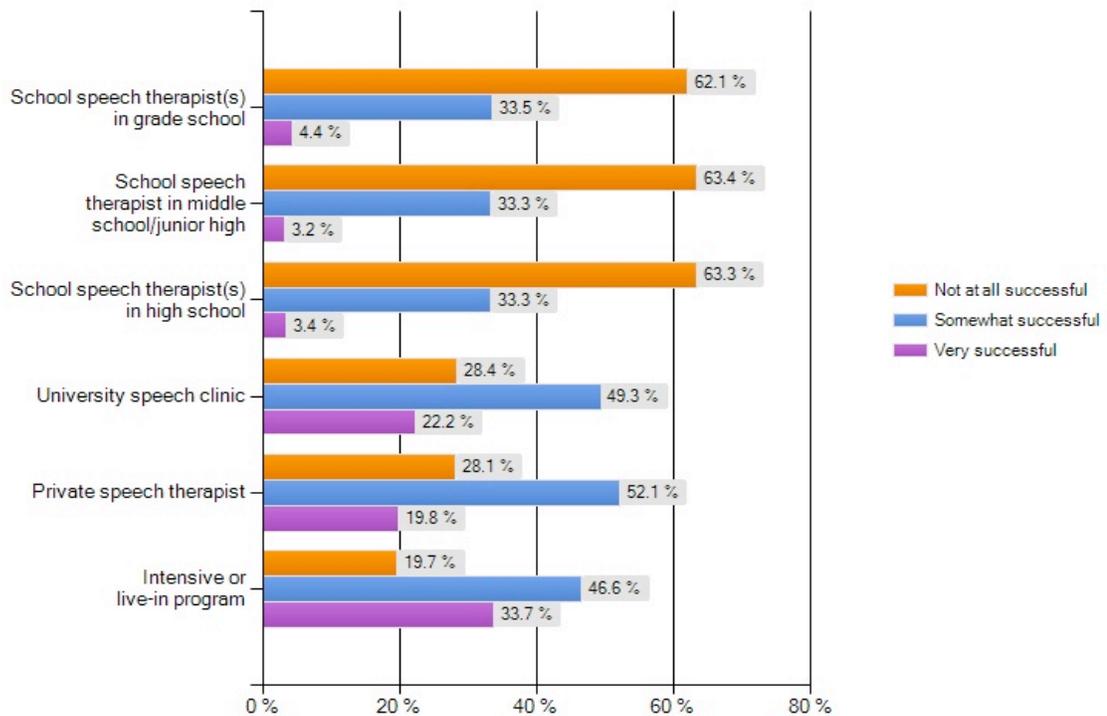
Speech Therapy

Speech therapy is the primary treatment for stuttering. While most survey respondents consider their speech therapy somewhat successful, results vary.

- 90% of the adults and teens surveyed have had speech therapy and 69% have had therapy as adults.
- 87% have had speech therapy more than once, and 35% have had speech therapy five or more times.
- 84% have experienced a relapse after improving their fluency in therapy.

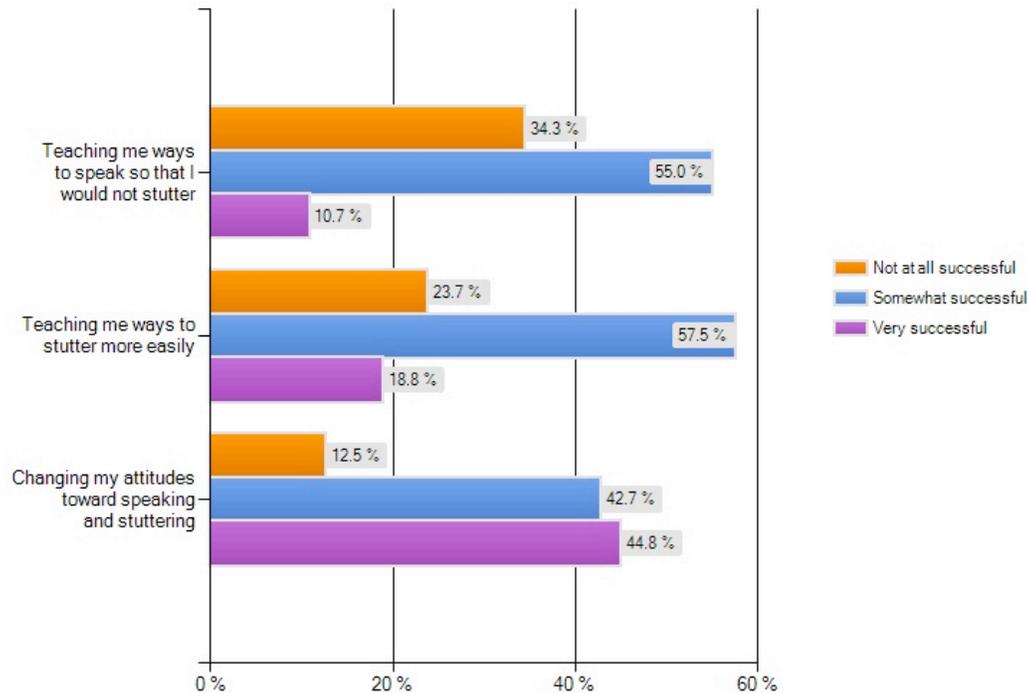
Most adults and teens have had better success with speech therapy from university speech clinics, private-practice clinicians and intensive programs than with the therapy they received in school. Teens reported higher rates of success than adults in school-based therapy and with private clinicians.

Where did you receive speech therapy, and how successful was each therapy experience? (Check all that apply)



Speech therapy is not “one size fits all.” Speech therapists use different approaches to treat stuttering and often combine several methods to meet individual needs. In general, survey respondents considered therapies that change attitudes toward speaking and stuttering to be more successful than therapies that focus primarily on speech mechanics.

Speech therapists use several different approaches to help people who stutter. Which approach(es) did your therapist(s) use, and how successful was it?



One challenge for people who stutter is that most speech-language pathologists have limited training and experience in treating stuttering. About one-third of adult and teen respondents had had speech therapy from Board Recognized Specialists in Fluency Disorders: clinicians who specialize in stuttering. Those who worked with a specialist were:

- More likely to have had speech therapy as an adult;
- More likely to have had a successful therapy experience with a private clinician or intensive program;
- More likely to have attended a stuttering support group.

Synergy between stuttering support and speech therapy

There is a positive correlation between stuttering support and speech therapy success. Active participants in NSA conferences and local chapters are more likely to:

- Have had speech therapy as an adult;
- Have had therapy with a Board Recognized Specialists in Fluency Disorders

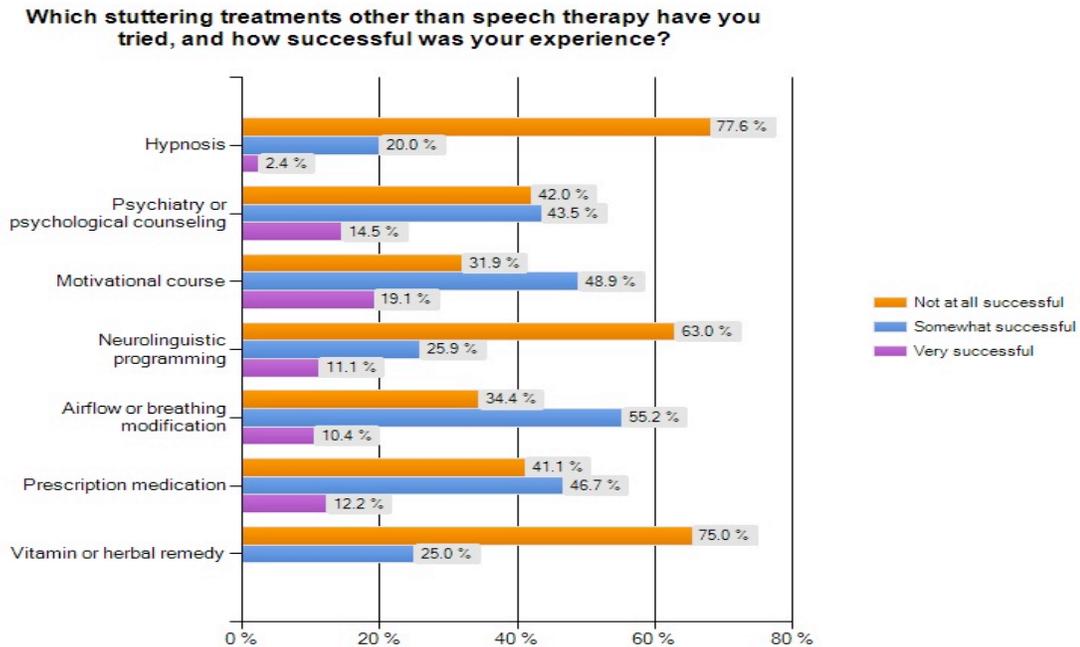
This correlation works in both directions: Some NSA members participate in support activities and then seek speech therapy; others undertake speech therapy and then are referred to support activities by their clinicians. About half of speech-language pathologists who are affiliated with the NSA say they have referred clients to the organization’s local chapters and annual conference.

Adults who participate in NSA chapters are more likely to consider their speech therapy successful:

Speech therapists use several different approaches to help people who stutter. Which approach(es) did your therapist(s) use, and how successful was it?		Participated in adult chapters in the last 3 years	
		YES	NO
Teaching me ways to speak so that I would not stutter	Not at all successful	39.3%	31.8%
	Somewhat successful	50.2	58.2
	Very successful	10.5	10.0
Teaching me ways to stutter more easily	Not at all successful	21.9	25
	Somewhat successful	56.7	59.9
	Very successful	21.4	15.3
Changing my attitudes toward speaking and stuttering	Not at all successful	12	14.2
	Somewhat successful	36.4	50.5
	Very successful	51.6	35.3

Alternative treatments

One-third of adult and teen respondents had had treatment other than speech therapy for stuttering. While some respondents had a measure of success with some treatments, none approached the success rate of speech therapy.



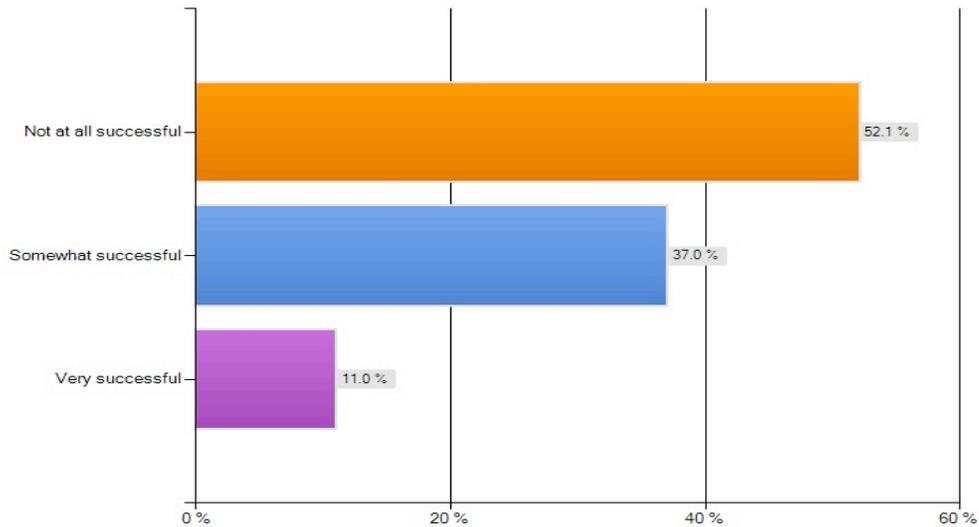
Assistive Devices

A small percentage of adults (73 people) have used assistive devices such as the SpeechEasy, Fluency Master and Edinburgh Masker.

- 66.7% used the device less than one year.
- 45% had speech therapy in connection with their use of the device. Those who did were more likely to find the device somewhat successful in managing their stuttering.
- 75% currently use their device rarely or never.

Of these, 11% say the device was very successful in managing their stuttering but 52% say it was not at all successful. There was little difference in success rates between the three most popular devices.

How successful has your experience with an assistive device been in managing your stuttering?

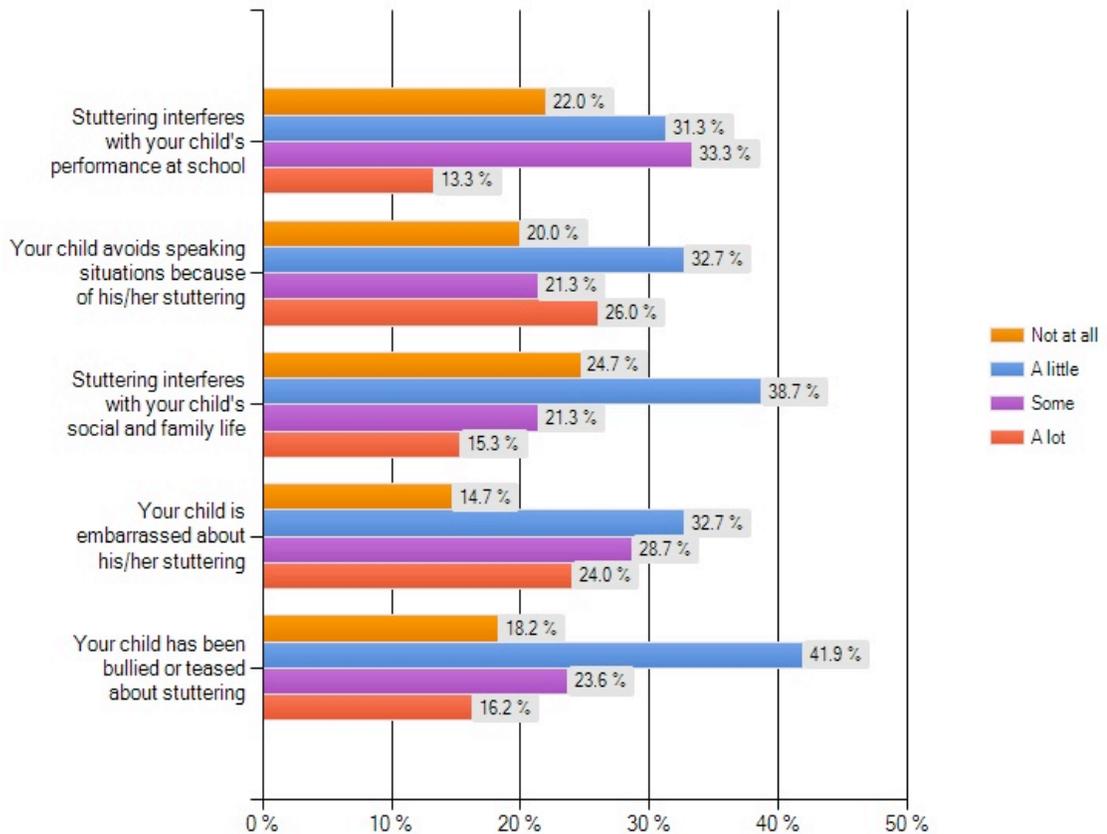


Children who stutter

Stuttering has the same impact on children as on adults

- Eight out of 10 parents say stuttering interferes with schoolwork, and that their children avoid speaking situations.
- 75% say stuttering interferes with family and social life, and 85% say their children are embarrassed about stuttering.
- One difference between children and adults is that more than 8 out of 10 children have been bullied or teased about stuttering.

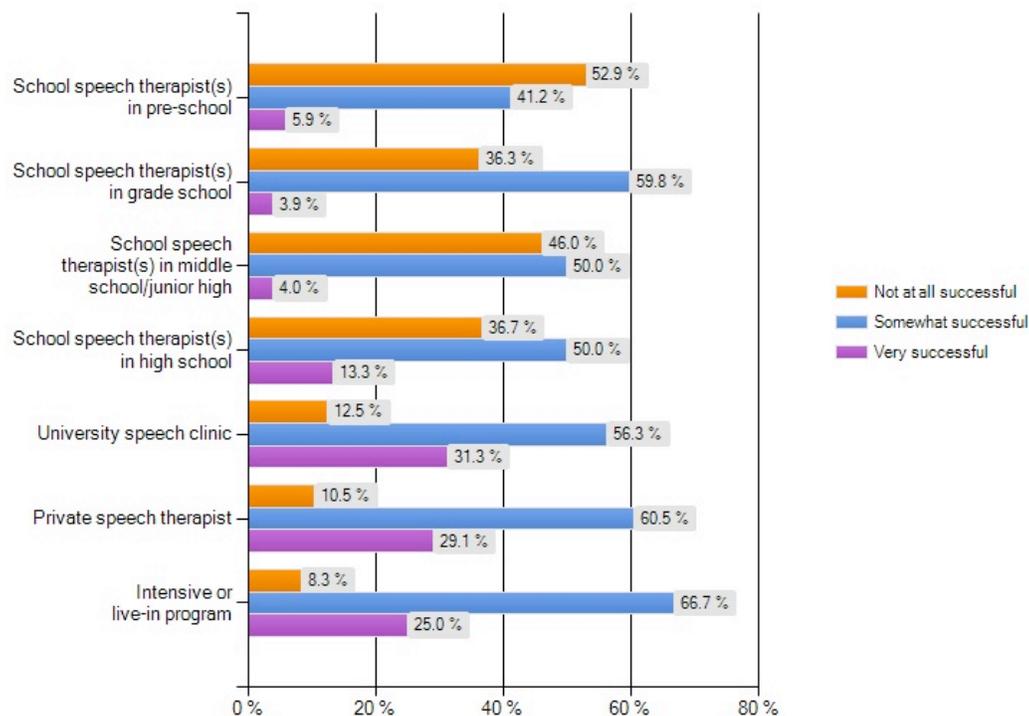
How does stuttering affect your child's life?



Speech therapy for children

- More than 90% of parents say their children have had speech therapy for stuttering.
- However, nearly 30 percent of parents were advised by professionals to postpone speech therapy until their children were older – despite a consensus among experts that early intervention is critical. This faulty advice most often came from pediatricians and physicians, but nearly as often came from speech therapists.
- 14% say their child has been denied speech therapy in school.
- In general, parents reported more successful speech therapy from university speech clinics, private-practice clinicians and intensive programs than from school speech therapy.

Where did your child receive speech therapy, and how successful was each therapy experience? (Check all that apply)



Like adults, children appear to have more success with therapies that change attitudes than with therapies that focus on speech mechanics.

46% of parents say their children have had therapy with a Board Recognized Specialist in Fluency disorders. Children who worked with a specialist are:

- Significantly less likely to avoid speaking situations
- Significantly less likely to find that stuttering interferes with social and family life
- Significantly less likely to be embarrassed about stuttering
- More likely to have had a successful therapy experience

Most parents have been involved with their children’s speech therapy. However, “homework” assignments to practice speaking techniques can be a source of friction between parents and kids. About half of parents say their children have discontinued speech therapy at some point.

About one-quarter of parents say their children have had treatment other than speech therapy for stuttering. Of these, significant numbers have had some success with psychological counseling, airflow or breathing modification, and prescription medications. A small percentage (11 children, primarily teens) have used assistive devices such as the SpeechEasy with mixed results.

Speech-language pathologists

- 60% of the SLPs who responded to the survey work in schools.
- They get information about stuttering from a variety of sources including professional conferences, journals, and the Internet.
- SLPs consider information on stuttering from the Stuttering Foundation of America and the NSA very useful for them and their clients, along with those organizations' web sites.
- Two-thirds are NSA members or participants. Half of the SLPs affiliated with the NSA have referred people who stutter to the NSA's support activities.
- Most are unfamiliar with the NSA's research committee.

NSA participation

More than two-thirds of the survey respondents are NSA members, former members, or participants in NSA activities. Of these:

- 37% have attended a NSA national conference in the past three years
- 48% have attended adult chapter meetings
- 9% have attended NSAKids chapters or youth days
- 25% have attended a continuing education workshop for speech-language pathologists
- 88% have visited the NSA web site
- 25% participate in one of the NSA's online groups.

How the survey was conducted

The National Stuttering Association's large membership enables the organization to survey a larger population of people who stutter than academic researchers can. The NSA works closely with leading speech-language pathologists and researchers but, as a consumer organization, does not endorse any specific treatment method.

The survey was conducted online on the SurveyMonkey.com web site. Invitations to participate in the survey were emailed beginning May 11, 2009, to the NSA's database of approximately 8,000 people, which includes registered web site visitors as well as members. Two follow-up emails were sent, and the survey was promoted on the NSA web site and NSA-sponsored Yahoo email groups.

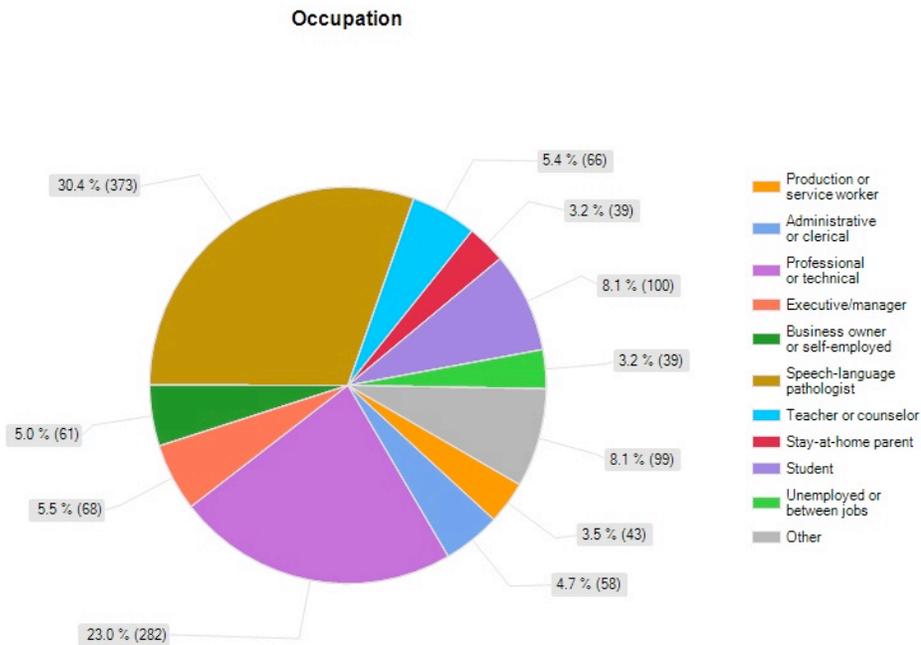
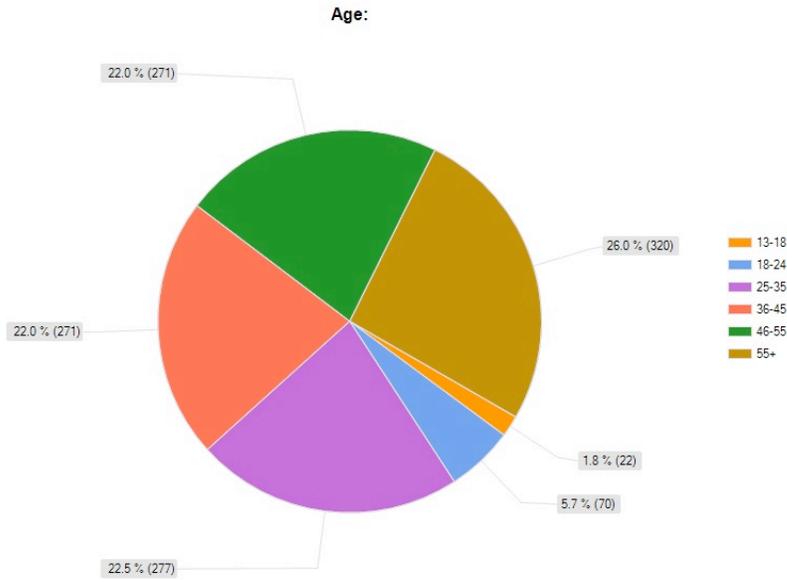
The 1,235 respondents included 851 who identified themselves as NSA members, former members, or participants in NSA activities: representing about 40% of this core group. 467 respondents identified themselves as paid members, representing 50% of the NSA's sustaining membership. Since the survey covered only people who were associated with the NSA or who had visited the organization's web site, it is not representative of all the estimated 3 million Americans who stutter.

The survey was conducted by James A. McClure, APR, Fellow PRSA, a public relations consultant and former opinion research director at Illinois Bell Telephone, Richard D'Amico, brand strategist and research director of the EGC Group advertising agency, and John Tetnowski, Ph.D., CCC-SLP, professor of communication disorders at the University of Louisiana at Lafayette. The questionnaire was reviewed by the NSA's research committee.

The questionnaire was based on a mailed-questionnaire survey conducted by the NSA in 2002 with 710 respondents. Where the same questions were used, the findings of this survey are consistent with the 2002 survey.

Respondent demographics

Adult who stutters	55.5%	686
Teen who stutters	2.5%	31
Parent/family member	13.3%	164
Speech-language pathologist	28.7%	354
		1,235



About the National Stuttering Association

The NSA is a non-profit organization that helps adults and children who stutter with support activities, educational programs, publications and advocacy. Founded in 1977, it's the largest organization of its type with more than 100 local support groups across the U.S. The NSA is directed by people who stutter, parents of children who stutter, and speech-language pathologists.

The NSA helps adults come to terms with stuttering and improve their communications skills, helps children and teens develop self-confidence, and educates their parents about stuttering. The organization helps consumers locate the best-qualified speech therapists and works with the nation's top speech professionals to promote stuttering treatment and research.

The National Stuttering Association's office is at 119 W. 40th Street, 14th Floor, New York, NY 10018, 800-(WeStutter) 937-8888, www.WeStutter.org.

National Stuttering Association
July 2009