StutterTalk Position Statement on
Self-Help and Speech Therapy for People Who Stutter

This statement is the official position of StutterTalk and is consistent with our mission of "supporting people who stutter, their families, professionals, students, and the general public by talking openly about stuttering and by providing information about stuttering." This statement was developed and reviewed by Peter Reitzes, Robert Quesal, Róisín McManus, Joseph Klein and Christopher Constantino. Published January 17, 2017. This statement does not necessarily reflect the views of all of StutterTalk's advisors and board members who are chosen for their diverse perspectives.

Introduction

Many people who stutter and their families have received tremendous help from speech-language pathologists, other people who stutter, and from support organizations for people who stutter. At StutterTalk, we do not endorse specific treatments or specific professionals. However, we do endorse talking openly about stuttering. We firmly believe that stuttering is okay, and for those who wish, changing how one stutters is also okay. It is our experience that speech therapy and self-help can often work in tandem to help people who stutter, families, and professionals face stuttering in productive ways.

Self-Help and Support Organizations

Many people who stutter grow up feeling alone and isolated with their stuttering. Some hide their stuttering and its impact for years from friends, teachers, co-workers, and even loved ones. Parents and family members also report feeling alone with this issue. The slogan of the National Stuttering Association (NSA) is, "If you stutter, you're not alone."

Some notable self-help organizations in the United States are the NSA, FRIENDS: The National Association of Young People Who Stutter, and SAY: The Stuttering Association for the Young.

The stuttering self-help community grew out of a desire to bring people who stutter together to help each other navigate life with stuttering. People participate in self-help for a variety of reasons, such as meeting others who share this unique experience, learning about stuttering, working on goals such as stuttering acceptance, changing how one thinks about stuttering, and learning about stuttering and different approaches to ameliorate the impact of stuttering. Self-help organizations bring people who stutter, family members, and professionals together to talk openly about stuttering, to learn from each other, and to listen to each other.

Many speech-language pathologists (SLPs) attend self-help conferences and workshops, and refer their clients and families to support organizations. Research has found that through participation in self-help, people who stutter report a range of benefits, including improved confidence, self-image and self-acceptance. Some people who stutter find that by participating in self-help they are better able to retain gains made in speech therapy and to communicate more easily. Research has found that self-help participation limits the internalization of negative beliefs about one's self and one's speech.

Speech Therapy

Speech-Language Pathologists are dedicated, caring professionals who are trained to help children and adults with speech and language disorders and their families. In the stuttering community, it is common to meet people who stutter, parents, and spouses who credit SLPs with changing their lives for the better. It is also common to meet people who stutter and families who report that speech therapy has not helped much and, in some cases, has even seemed to make their struggles with stuttering "worse." For example, some people who stutter report feeling like failures after speech therapy because they can't use the speech "tools" they are taught in the treatment room in "the real world" when the tools are needed. Other people who stutter report feeling that their specific speech therapy experiences taught them to believe that stuttering itself was a type of failure. Some parents report feeling frustrated and desperate after years of speech therapy because their child is not "better."

At StutterTalk, we advise individuals seeking professional help to ask many questions and to make careful choices. For example, when seeking an SLP, StutterTalk suggests asking professionals many questions such as the following: How much experience do you have working with people who stutter? What approaches do you use? What type of long-term outcomes have you had with other clients who stutter? Why do you enjoy working with people who stutter?

As the therapeutic relationship is built upon trust and understanding, let yourself "shop around." If you don't feel comfortable with the first therapist you meet, visit with another. StutterTalk also suggests asking professionals if they use one approach with all people who stutter or if they individualize treatment to meet the specific needs of each client. As the saying goes, "One size does not fit all."

Speech Therapy for Adults

In general, adults who stutter can expect to live with some form of stuttering for the rest of their lives. As a result, most speech therapy for adults is focused on managing stuttering, not curing it. Adult treatment should generally focus on areas such as reacting productively to stuttering, talking openly about the physical and emotional experience of stuttering, learning to advocate for oneself, and, if one wishes, learning a range of strategies to stutter differently or stutter less. Some speech therapy for adults who stutter focuses exclusively or primarily on "fluency." While this may benefit some people who stutter, many have reported that "chasing

fluency" only leads to more frustration and to unhealthy attitudes about communication and about themselves.

In general, StutterTalk advocates a broad treatment approach which includes talking openly about stuttering, some level of stuttering acceptance, and exploration of different speaking strategies to help individuals change their speech and learn ways to move forward. StutterTalk holds the belief that stuttering openly is always okay. It is our belief that *saying what one wants to say while stuttering is far better than silence.*

Strange as it sounds, for some people who stutter — especially those facing avoidance issues such as changing the words they want to say — stuttering more (not less) may be a sign of progress. For example, adults who usually avoid talking during meetings may begin to stutter more as they take risks, such as choosing to speak and stutter rather than sitting silently. Often more stuttering will occur because an individual is choosing to say the words they want to say, rather than only choosing words they can say fluently. This is a sure sign of progress. In addition, many people who stutter report that by focusing more on speaking up and less on "fluency," speaking actually becomes easier.

There are many wonderful written resources in addition to speech therapy and support group participation for adults who stutter. One of our favorites is the Stuttering Foundation's seminal book, *Advice to Those Who Stutter*.

Preschool Treatment

Preschool stuttering treatment should be fun and unstressful for the child. This treatment typically focuses on the therapist and parent changing the communication environment (such as modeling a slow rate of speech and employing verbal turn taking) or administering specific verbal responses after the child speaks (such as, "That was nice smooth talking," and, "That was a little bumpy, say it again"). Some SLPs integrate (combine) aspects of these treatments in their work with preschoolers who stutter.

In general, preschool stuttering treatment looks very different from speech therapy for school-age children and adults. Most leading experts agree that preschool therapy (approximately 2-6 years of age) focuses on training the parents to administer treatment. Instead of asking preschoolers to change how they talk, parents are responsible for reducing their own speaking rate, instilling turn taking, providing specific verbal responses, or using other such strategies.

For this reason, stuttering experts agree that *a parent should attend all or most preschool therapy sessions* so that the parent may practice the strategies with an SLP, learn to problem solve, and keep data at home while carrying out the agreed upon treatment. In a way, parents become co-therapists and help figure out what is "working" and what is unhelpful. The SLP and parent regularly review data together to make treatment decisions.

Unfortunately, and for a variety of reasons such as busy schedules and degree of familiarity with evidence-based treatments, many SLPs are reluctant to include parents in preschool stuttering treatment. Parents may wish to familiarize themselves with evidence-based preschool treatments such as the Demands and Capacities Method, the Lidcombe Program, and Palin Parent-Child Interaction Therapy. If the SLP is not using an evidence-based treatment approach with a preschooler who stutters and not inviting a parent to participate in sessions, parents should ask the SLP why.

Preschool stuttering treatment is also different from adult treatment because most experts view the end goal to be a very low level of stuttering or full recovery from stuttering. Considering that the majority of preschoolers who stutter, about 75%, recover without treatment, many think that recovery is a reasonable goal of treatment for this group. At the same time, a good portion of preschoolers who stutter will continue to stutter into their child and young adult years. For this reason, it is stressed that preschool treatment should offer positive and healthy attitudes about stuttering and communication. While the end goal may be full recovery, this will not always be achieved no matter how good the therapy or parental involvement. The child and parent should be encouraged to remember that stuttering is always okay and should never be punished or viewed as a failure.

Some have expressed concern that working towards recovery may lead to the preschool child developing negative feelings and a negative self-image if they continue to stutter. These are reasonable concerns. We suggest that families, children, and therapists speak openly about them. Observing an experienced and talented SLP do this work goes a long way towards demonstrating to parents and others that the work is fun, positive, and non-punitive.

School Age Speech Therapy

Approximately 75% of young children who stutter will recover within about four years. Some children recover from stuttering within a year or less. For those who continue to stutter into the school-age years, treatment often resembles adult speech therapy. Students learn to explore their feelings about stuttering, advocate for themselves, and are exposed to strategies to move forward in speaking. In general, recovery or total "fluency" are not realistic goals for this group of children, and seeking such goals may lead to negative feelings about communication and about oneself.

Here are three important things to know about school-age children who stutter and about stuttering in general.

> *Variability:* Stuttering is variable. A person may go hours, days, weeks, months or even years without much noticeable stuttering, and then the stuttering seems to reappear. While this can be very frustrating, it is *normal* and to be *expected.* The amount of stuttering an individual experiences may vary

depending on a wide range of possible variables across different speaking situations. For example, some people report stuttering more when they are tired, sick, or experiencing stressful situations. Some people report stuttering more while reading, while others report stuttering less when reading. Some may stutter more when speaking with authority figures while others may stutter less. This speaks to the complicated and individualized nature of stuttering. It is important not to blame people who stutter for these fluctuations in stuttering. It is also important not to blame parents or SLPs for the variability of stuttering. Stuttering is no one's fault.

Therapy Room vs. The Real World: Like adults, many school-age children and adolescents are able to use a range of speech "tools," such as rate control, easy onsets and voluntary stuttering to reduce their stuttering in the therapy room. But it is widely reported that it is harder to use such strategies in the "real world," such as in a classroom or in a cafeteria. Many have stated that *speech tools are hardest to use when they are most needed*. Some people who stutter find speech tools useful, and others use them rarely, if at all. As people who stutter mature, they may choose to focus more or less on speaking strategies. For example, an adult who is graduating from college and beginning to interview for jobs may view speech tools very differently than a child in school.

Fluency vs. Effective Communication: To some extent, *school-age children who stutter are children with an adult problem*. Asking children or adults to monitor their speech all day is an onerous and stressful, if not cruel, task. If one wishes to focus on changing speech and reducing stuttering in speech therapy, StutterTalk suggests that SLPs and parents present speech "tools" as *options* the child has if he or she chooses to use them, rather than tasks or expectations imposed upon a child.

Being a child who stutters is very challenging. To different degrees, many children who stutter learn to choose avoidance and silence over speaking with a stutter. For example, a child who knows the correct answer to a question in class may choose to remain silent or to answer incorrectly because the correct answer feels too difficult to say without stuttering. The reasons for this are many, and range from fear of teasing to fear of disappointing a parent, therapist, or teacher. StutterTalk believes that effective and enjoyable communication is based on *saying what you want to say when you want to say it*. StutterTalk also recognizes that moving forward through words is physically and mentally frustrating for many people who stutter. Exposing children to a variety of speaking strategies — such as stuttering on purpose to reduce the fear of speaking and stuttering, and slowing rate to reduce stuttering, without any expectation that they are used all the time — can be productive. Some refer to this as *planting seeds.* As children mature they may choose to use such strategies when they need them.

> Children who stutter are faced with a choice many times a day: speak or remain silent. Every time a child stutters they have chosen to speak. Even though stuttering can be scary, embarrassing, and physically unpleasant, they have faced their fears and chose speaking up over silence. Rather than a failure of fluency, every stutter is a victory over fear. At StutterTalk we believe children who stutter are very brave.

Seeking Help

While all speech-language pathologists want to help their students and clients, many SLPs report feeling unprepared to work with people who stutter. To be blunt, not all SLPs "get" stuttering and not all SLPs feel they have adequate training or experience in treating people who stutter. Stuttering or Fluency Disorders is not even a required course in some speech-language pathology graduate programs. For these reasons, people who stutter and family members should make careful, informed decisions when choosing an SLP or other professional.

If you are looking for an SLP to work with, two good places to start are The Stuttering Foundation's referral list and the American Board of Fluency and Fluency Disorders Find a Specialist list. There are many excellent professionals on these lists but there are also many excellent professionals who do not appear on these lists. Consumers are urged to carefully consider any professional, regardless of credentials. Many people find great therapists through the stuttering community "grapevine." Asking other people who stutter or parents at local support groups or self-help conferences is a great way to learn about good therapists in your area.

Speech Therapy in the Schools

Public school SLPs are dedicated, caring professionals who work with children with a wide range of issues such as language delays, articulation delays, autism, apraxia of speech, developmental disabilities, intellectual disabilities, hearing impairments, and fluency issues such as stuttering. Most public school SLPs do not specialize in stuttering treatment. Some, perhaps many, public school SLPs may focus primarily on "fluency" with school-age children who stutter, while overlooking goals related to helping students gain positive attitudes about stuttering and communication, learning about stuttering, risk taking such as speaking in class, and self advocacy such as meeting with teachers regarding reasonable classroom accommodations.

If your child is eligible for speech-language therapy in the public schools, it is likely that your child will work with the SLP assigned to the school. Unfortunately, most school districts do not employ stuttering specialists who travel from school to school working with children who stutter. Parents should strongly consider having open conversations with their child's SLP regarding goals, treatment, and expectations. Parents should consider talking to their child's SLP about the importance of fostering healthy attitudes about speaking and stuttering. Parents may need to explicitly explain to the SLP that stuttering is okay and that speech therapy can and should address much more than just "fluency" and reducing stuttering.

Parents should strongly consider suggesting that their child's SLP seek out trusted resources such as the Stuttering Foundation, the NSA, FRIENDS, and SAY. For example, the Stuttering Foundation offers *Workshops for SLPs,* which are intensive training sessions for professionals who want to learn more about stuttering and stuttering treatment. FRIENDS and the NSA also offer wonderful workshops for professionals.

Empowered and Informed Consumers

Facing stuttering can be both frustrating and incredibly rewarding. We have come to believe that people who stutter and their loved ones do much better when they have access to information and the support of others having similar experiences. People who stutter and family members will have many questions as time goes on. For example, is our time with an SLP helping us? Will meeting other people who stutter help me? Should we stop school-based therapy and find a private specialist? Will I lose my job if I tell my boss I stutter? Are we focusing on the right things in therapy? Do I want a break from therapy to focus on other areas of my life?

The good news is that there are a lot of people out there who have successfully found their way through and are now creating resources to help you navigate this. Ask yourself or your child what they need, reach out for help from the organizations mentioned above, ask lots of questions, and do your best to make careful, informed decisions.