

**Keynote speech—Barry Yeoman**

*NYC Stutters conference, May 15, 2016*

*As prepared for delivery*

Thank you, Darren. And thanks to all the organizers for making this event happen, and for inviting me as the keynote speaker, and to all of you for listening. I'm welling over with appreciation for the efforts of the New York City chapters to launch a conversation about, and maybe even redefine, what it means to be a stuttering community in 2016 and beyond.

This is something of a homecoming for me. Although I've lived in North Carolina for more than 30 years, that's not where I began. In 1979, after growing up in the Long Island suburbs, I moved into a dormitory at NYU, where I was starting the second semester of my freshman year. As an undergraduate, I lived in various neighborhoods, from Washington Heights to Park Slope, but mostly in Greenwich Village, near NYU's campus.

There are places all around here that are iconic to me, because they represent what it means to claim your place in a city, and in a society, where you are viewed as less than equal. In my late teens and early twenties, the realization that my friends and I had a voice to assert our full participation was a heady notion, and one that has stuck with me in the 3½ decades since.

Fourteen blocks from here is Sheridan Square, which, when I moved here in '79, was the center of a vibrant gay community—and, although I didn't fully understand it at the time, was maybe one of the reasons I chose NYU. That vibrancy was new, and it owed itself to something that had happened 10 years earlier: a three-night rebellion that followed a routine raid on the Stonewall Inn, on Christopher Street right off 7th Avenue.

One reason the police felt like they had license to raid gay bars, to arrest vulnerable men and women—some of whom were not out to their parents, their employers, their spouses and children—was because homosexuality in 1969 was viewed as a pathology. It was listed in the DSM, the Diagnostic and Statistical Manual of Mental Disorders, the Bible of the mental-health profession, first as a “sociopathic personality disturbance”—despite research to the contrary—and later as a more benign psychiatric disorder.

It was medicalized, with the consent of certain gay leaders, who believed this would lead to more humane treatment than viewing homosexuality as a sin or a moral failing. Moving beyond that acquiescence to the medical model, into a proud and joyful claiming of identity, took a new generation of leaders, most of them young.

Remember the Stonewall Rebellion. I'll come back to it later.

Equally important in my geography of this neighborhood is St. Vincent's, now closed, but once the flagship hospital of the Catholic church in New York City. I was a junior at NYU when the first reports emerged of a constellation of rare diseases that were killing gay men—rapid, ugly deaths that baffled physicians and scientists. As the hospital serving Greenwich Village, St. Vincent's was home to the first and largest AIDS ward on the East Coast.

But it was not always like that. Initially, patients were not admitted to rooms but rather languished on gurneys in the hallways. There were numerous reports of inhumane treatment—including, famously, an assault on a gay couple by a security guard. It was this, among myriad other life-threatening indignities, that led to the formation of ACT UP, the AIDS Coalition to Unleash Power, one of several grassroots groups that seized and changed the conversation—and in the process saved untold numbers of lives.

Remember ACT UP. I will come back to them later.

I want this speech to be a little provocative—not for provocation’s sake, but rather to get us thinking more expansively about the potential for our community.

Most of us, when we walk into our first big stuttering conference, are presented with an agenda, a set of goals, created by those who run the organization—some of whom stutter, some of whom don’t. It can be so emotionally overwhelming to be—for the first time!—among hundreds of other people who stutter that maybe we don’t take the time to evaluate that agenda, to figure out whether it syncs with our own agenda, even to contemplate what our own agenda might look like.

After having spent our childhoods and early adulthoods shuttling from one speech therapist to the next, learning about this fluency-shaping technique or that razzle-dazzle device, we lack the context for stepping back, clearing the slate, and asking: What can this community look like at its best, at its most compassionate, at its most empowered?

I have some thoughts. Surely you have thoughts, too. Please allow me to launch the conversation.

To understand where I’m coming from, I think it’s useful to go back to 1979, when I first showed up at Weinstein Residence Hall just off Washington Square. I arrived as a bright, skinny, awkward freshman, the former editor of my high-school newspaper, and someone whose body had failed me utterly. Growing up, I couldn’t throw a baseball, couldn’t play the clarinet, couldn’t muster the attraction I was supposed to feel toward women.

Needless to say, I also couldn’t talk. After a decade of failed therapy—bounces, prolongations, delayed auditory feedback, Marilyn Monroe-style breathy speech—my parents had finally taken me to Dr. Martin Schwartz, whose book *Stuttering Solved* promised a success rate—success meaning fluency—of 94%. All you had to do was treat stuttering mechanically, mastering passive airflow, and you would never stutter again. *Bam*. Simple.

I remember the intake interview with Dr. Schwartz, right after my high-school graduation. My parents were there too. The nationally known stuttering expert looked at me and said, “I have one question for you: What is your name?”

As my face contorted like a ghastly mask, and stray syllables tried but failed to leave my lips, Dr. Schwartz sat back, satisfied at achieving the effect he hoped to produce. *Take my two-day group workshop*, he promised, *and you’ll never suffer this humiliation again*.



I remember those two beautiful days of fluency. I was 18 and was offered the promise of normalcy. During my undergraduate years I dutifully attended what Dr. Schwartz called a support group in New York City, which was really a series of gatherings in someone's living room to practice passive airflow. The notion that people who stuttered could get together and improve our *own* lives without the mediation of a doctor was beyond the realm of possibility for any of us back then.

And when I slipped back into the severe stutter, I didn't need Dr. Schwartz to tell me what I already assumed I knew: that it was my own fault for not trying hard enough.

What a difference between how I was treating my stutter and how I was treating the newfound realization that I was gay. At NYU, surrounded by other gay and lesbian friends, I moved quickly past shame and into the hopefulness of self-discovery. I dated men; I had late-night conversations with other gay friends in the dorm lobby; we went out for midnight meals at Phebe's Tavern on the Bowery and smiled in recognition at others whom we recognized as kindred spirits.

I marched in my first pride march, got arrested at a sit-in when New York City Council refused to pass an equal-rights bill, spent countless hours hunkered down at a gay history archive on the Lower East Side for my senior thesis. I learned about how the Gay Liberation Movement that followed Stonewall was instrumental in the removal of homosexuality from the DSM, the mental-health Bible, in 1973.

None of this was easy. Gay relationships were illegal in New York until 1981, and violence was rampant. Personally, I had a negative body image to fight and old shame to pack away. But at least I knew the endgame: a playful, intimate life, embracing my sexuality and the community it brought me, seizing from better educated straight people the power to define me.

After college, I moved South and launched what has become, a little to my surprise, a successful journalism career. By then I had drifted away from Dr. Schwartz, but I continued attending university speech clinics. I swear, I went through student clinicians faster than I went through college boyfriends, and I think I might have worked their every last nerve. My nerves were pretty shot, too, as I sat in traffic each Monday afternoon at 5, en route to a speech-therapy session that I knew would bring me neither fluency nor peace.

One progress report from 1988 described me as "resistant." It went on to say and I'm quoting here:

*Therapy sessions began to be dominated by discussions of Barry's frustration with his dysfluency, with only a little time left to work on breaking up his blocks. Barry began to feel that desensitization exercises were making him increasingly afraid of stuttering and of speaking situations in general. It became apparent that Barry would need to work on reducing the non-speech-related stresses in his life before he could adequately deal with his stuttering. After a weekend at the beach, Barry decided to take a break from speech therapy.*

What came next was my own personal experience. I'm not suggesting it will work for you, since we all have our own needs, and our own styles. Plus, the times are different. Speech therapy, in some cases, has gotten considerably better. But it sure worked for me back then.

I decided to make that break from speech therapy permanent. I packed my bag of tricks and never went back. I was 27 and *done*.

It helped that, in the late '80s, we were in the throes of the AIDS crisis, which put my stutter into some perspective. Before anti-retroviral drugs made the disease manageable in the mid-'90s, HIV killed 300,000 gay and bisexual men in the United States alone. I knew some of them—lost three of my best friends in '88, '89, and '93—and like many of my friends I watched vibrant lives sputter out unpredictably just as they were taking on definition.

I also watched as ACT UP grew into a national force that literally stopped traffic, disrupted conferences, refused to budge from the headquarters of drug manufacturers. In the process, ACT UP and its spinoff, the Treatment Action Group, succeeded in moving new medicines through the research pipeline and into patients' hands with record speed. With lives at stake, priorities became clear, and polite deference to the powers-that-be was low on the list.

The four years after I quit speech therapy followed a course that was reminiscent of my coming out as a gay man. I de-medicalized stuttering for myself—stopped thinking of it as a condition that needed to be fixed by professional intervention. (Ironically, as an aside, over the next few years I began stuttering much less.)

I came out of the closet—that is, I wrote a column about my stutter for the newspaper that employed me. And I found a community of supportive, successful, funny, ethical, good-looking people like yourselves whose common bond was our stutter.

For me, that community was an international one, as my first gathering was the 1992 World Congress of People who Stutter in San Francisco. It was hosted by NSA's predecessor, the National Stuttering Project, or NSP. Now, NSP was no ACT UP. They were not getting arrested outside Michael Palin's office to protest the demeaning depiction of people who stutter in *A Fish Called Wanda*.<sup>1</sup> But what thrilled me was that this was definitely a movement of stutterers doing it for ourselves.

Some of the NSP's veterans drew inspiration from the civil rights movement, the feminist movement, the gay and lesbian movement. They had watched the emergence of Deaf culture—particularly the Capital-D Deaf culture that rejected the premise that deafness was a disability that needed eradication. Capital-D Deaf folks had, and have, no interest in hearing or speaking vocally, thank you, because what they were building was just as rich in communication as mainstream hearing culture.

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<sup>1</sup> Note: NSP did, however, picket peacefully outside MGM's offices in Culver City, California. See <http://lat.ms/1TOBZPX>.



And of course, the self-help leaders I met back then knew about the larger disability-rights movement, which, at its best, joined forces with other minority groups to demand equal treatment. You'll more about the disability-rights movement later from Chris and Emma.

The self-help movement that I first encountered in the '90s didn't reject speech therapy or exclude the professional community. SLPs were welcome, as long as they understood that we who stuttered were steering this particular ship. There was a pretty wide range of perspectives within an NSP conference. But, for the first time, I was among people who were creating a space for the idea that *we* held the answers. Not the experts. Not the scientists. We did.

In that space, some of my friends and I created an informal network called Passing Twice for LGBT people who stutter and our allies. (Elizabeth Kapstein, I'm looking at you.) We quickly recognized that the lessons of post-Stonewall gay liberation, and maybe even ACT UP, were relevant to stuttering too.

We could celebrate diversity; form communities; support one another as we built productive lives and careers; help one another through the hard times; and seize control of our own narratives, declaring that we didn't need to be changed. To the degree that we intersected with speech professionals, it was on our terms, focused on our goals—and for most of us, secondary to what we could provide each other.

I think it's no secret that the self-help movement has grown more professionalized over the past 20 years. NSA, an organization that continues to mean a lot to me, sponsors clinical and research symposia that confer continuing-education credits on SLPs. It has an ambitious plan to raise millions for research. It talks about promising medications and genetic discoveries that can vanquish stuttering once and for all. This can lead to contradictory messages: *We are the cure. We need a cure.*

I understand that these contradictions, that these tensions, can make us stronger as a community. I also want to convey my respect for those who see research support and professional development as important goals for the self-help movement.

And I know that my perspective comes from a place of privilege. I have a college education, a good career, and reasonable financial stability, and that allows me to take the long view rather than thinking about fixing my speech so I might land a restaurant job. I can survive without fluency. What's more, aging has brought me certain normal neurological changes, which means I stutter less at 55 than I did in my 20s and 30s.

With that on the table, it still seems to me like these two sentences—*we need a cure* and *we are the cure*—represent the juncture at which our movement stands. And from my perspective, I agree strongly with former NSA chair Kenny Koroll, the first person I ever heard say the words, *we are the cure*.

There is a place for research about stuttering, as long as it's conducted ethically—and not used, for example, for genetic selection for fluency. And, my God, there is certainly room for

improving stuttering therapy. People who stutter should have strong inputs into both of these arenas.

But if we think of these as two main pillars of our movement, I fear we're losing an opportunity to take control of our lives, to build a compassionate community—in short, to put the “self” back into self-help.

While it's not up to me, nor up to any individual, to dictate where the movement should be heading, I'd nonetheless like to suggest some alternative courses for the next generation to consider.

I see the potential direction of the movement as two-fold: to make our own lives better, and to serve the millions who stutter but might never show up at our conferences. Let me suggest some goals in both departments.

On the individual side, I want to make sure that everyone who stutters feels like there's a place they can come for mentoring. That they feel like there's somebody they can turn for career advice, for dating advice, for advice about dealing with their parents or their therapists. I want everybody who stutters to know that when they're having a bad day, there's somebody they can call and vent to.

I want a self-help movement that fosters the idea that we who stutter can do so uninhibitedly, focusing on the meaningful things we have to share, and maybe even enjoying the syncopated rhythms of our stuttering, rather than fixating on our shortcomings in achieving fluency. I want this to happen at the chapter level, at the regional level, at the national level, at the global level. I want the national organization to provide local chapters with the resources they need to make this happen.

I want a movement in which every child, every young adult who finds us understands—from the start—that speaking with a stutter, even a severe one, is an option, that there is no shame in it, and that there is in fact music in it.

I want them to understand that speech therapy is an option, too, but it's not the only option. And that if we choose it, we get to decide what type of therapy we need.

I want everybody who walks into a chapter meeting, or a regional or national conference, or a world congress, to feel like they've come home. I want them to feel equally at home whether they are severe or mild or covert or young or old or black or white or Asian or Hispanic or Native American or gay or straight or poor or affluent or college-educated or not. I want a movement that is introspective enough to figure out who is not in the room, and why, and then proactive enough, and culturally competent enough, to reach out and include them. And by “include,” I mean not just at a participation level, but at a decision-making level as well.

On the social side, my ideas are more specific. As I said earlier, they're informed by the post-Stonewall gay liberation movement; the life-saving direct actions of groups like ACT UP; my



own early days in the stuttering self-help world; and such profound community-building efforts as capital-D Deaf culture.

At the World Stuttering Congress in The Netherlands in 2013, the British novelist David Mitchell—*read his books*—surprised many of us by calling stuttering (or, in his words, stammering) a political issue.<sup>2</sup>

“No one’s expecting us to march on Parliament with megaphones,” Mitchell said, explaining that we’re perceived to be politically marginal and small in numbers. “Which we’re not,” he added. “There’s millions of us, but to become politically active, first you have to out yourself as a person with a stammer.”

So with Mitchell’s words in mind:

I want every person who is applying for a job with a corporation, a university, or a government agency to know that the HR manager has been educated *by us* about stuttering: how to talk with us, how to listen to us, and how to understand communications competency in a way that’s broader than fluency. I want stuttering awareness to be part of workplace diversity training because *we* put it there—we demanded its inclusion and provided the perspective that’s lacking in many workplaces now.

I want everyone who has faced discrimination because of their stutter to know that there’s a local self-help chapter that has their back; and a regional chapter that has the back of the local chapter; and a national organization with the legal muscle to blow the offender away in court. I want would-be bigots to be afraid of a lawsuit coming from the stuttering world, and to modify their practices accordingly.

I want some of that legal muscle to be harnessed toward a lawsuit that will determine, once and for all, that people who stutter are covered under the Americans With Disabilities Act. Disability does not mean that we’re incompetent. Legally, we are disabled when someone—say, an employer—thinks we can’t do the job and acts on that prejudice.

If any keynote speaker addresses our conferences and suggests we should *not* have access to the courts—as I’ve seen happen—we should feel empowered enough to challenge them, and maybe even to boo them into reconsideration.

I want every movie producer who uses stuttering as a cheap proxy for weakness, repression, or moral failing to expect an organized, visible backlash. To quote David Mitchell again: “Public figures who mock stammerers—this should be as much a no-go zone as blind people or the use of racist terminology. Politically, we need to illuminate public ignorance.”

Here, again, we can draw inspiration from gay and lesbian activists, who organized colorful and effective street-theater protests against negative media depictions, especially during the early days of the AIDS crisis. One of the groups doing these protests was called the Swift & Terrible Retribution Committee. We could use one of those, no?

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<sup>2</sup> Video at <https://youtu.be/IJM0eqfq5fE>.

I want a movement with the power to shut down every scam artist who peddles a miracle cure. And I want every person who stutters to have access to information, produced by us, about what's truly obtainable and desirable in speech therapy. I also want them to know that supportive psychotherapy, or *no* therapy, might be an equally reasonable or even better option. In the longer term, I want us to be strategizing about how to create both an organizational culture and a larger society where people who choose to just keep stuttering, and to reject the notion of stuttering as a medical disorder, feel fully embraced.

I want us to hold researchers' feet to the ethical fire. I don't want to say "I told you so" the first time a fetus is aborted because it had some stuttering genes.

And finally, I want a movement that collaborates with other movements of traditionally marginalized people, making us all stronger.

I could continue, but I want to leave time for your ideas too. So I'll end with some words I heard last week from Mia Birdsong, who helps run the Family Story Project, a group in Oakland, California that is transforming the stories that families tell about themselves. Her words are about people who live in poverty. But as I listened to them, I realized they could just as well apply to us.<sup>3</sup>

"We cannot wait for somebody else to get it right," she said. "Let us remember what we are capable of. Instead of trying to alter the fabric of existing ways, let's use some of our collective power toward inventing and bringing to life new ways of being that work for us."

Thank you.

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<sup>3</sup> Video at <http://n.pr/1QTXFNQ>.