

# **From Non-Verbal to Motivational Speaker: The Abridged Version**

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Good morning! Thank you for this opportunity to speak with you today.

I am Glenda Watson Hyatt, an author, motivational speaker and badass agitator. I inspire people who are silently screaming “There’s more to me!” and yet they are standing in their own way from moving forward. By sharing my own unique life experiences, I motivate audiences to identify their dreams and to take action.

The journey from non-verbal speech impairment to motivational speaker has been quite a long and winding road, and is partly thanks to the advancement in technology. Today I am not here to inspire you to identify your dream, even though I would love to. Perhaps that opportunity will arise another time. Rather, today, I am here to share with you my journey, my history, with communication.

Before I share my story about communicating, I would like to mention this is my journey coloured by my personality, my knowledge and attitudes, my upbringing, my connections in the world.

Other individuals with speech and language disabilities, including those who use AAC, have their own set of experiences unique to them. Although there may be similarities, their journeys, their stories will differ from mine. The differences are determined by many factors, including available resources: technological, financial and social, and decisions made at the time.

As you may have guessed, I have cerebral palsy, which affects my speech, balance and muscle coordination. My physical movements are jerky and involuntary; one body part or another is in constant motion. My left hand has some function, while my right hand is generally in a tightly clenched fist. I am not able to walk without support and my speech is difficult to understand.

My inability to walk independently is fairly easily accommodated with a small electric scooter for indoors, this larger one for outside and a manual wheelchair for backup.

That said, somewhere in my possession I have a letter from a medical specialist, written when I was young, stating my diagnosis is quadriplegic athetoid cerebral palsy, that I am functionally non-verbal and that I require 24-hour nursing care.

Besides stating that I would require 24-hour nursing care, which is factually untrue, the label “functionally non-verbal” is the most burdensome load I’ve had to carry over the years. Being labeled, and hence seen, as functionally non-verbal, has often seen me staying quiet even when I had something important to say.

Here's an example: one day in Kindergarten, the occupational therapist put my heavy, metal, long-legged braces on backward. I knew he was putting the wrong brace on the wrong leg, and it downright hurt. But because I felt he wouldn't understand me, and because I didn't want to create a big hassle by insisting he try to decipher what I was telling him, I didn't say a word. I, at five, just muscled through.

Only people close to me understood *Glenda-ish*.

That label was embedded as a part of my identity to future service providers and, equally as important, how I viewed myself. That was up until five years ago when I realized the weight of letters written, of notes made in files. These words are often necessary to play the game to get a much-needed service, equipment or medication to live with a disability. But these notes also colour how the next service provider sees me and prepares themselves to work with me.

Those labels are very much based in the medical model in which the disabled person is seen as the problem, something that needs fixing or curing. Usually the focus is on the impairment, rather than the needs of the individual. We are to be adapted to fit into the world as it exists

At the same time that I realized the weight of the labels imposed on me by others, I also realized I, and only I, can choose the words that accurately define and describe who I truly am. This is my own truth.

From that point forward, I have described myself as having a significant speech impairment, not as "non-verbal".

Because of my speech impairment, I continue to discover and develop various methods to communicate. I am fully capable of seamlessly flowing between methods depending upon the situation.

In sharing my history with communicating and how I came to be where I am today, I would like to highlight several key steps along my journey. Many of these highlights I have pulled from my autobiography *I'll Do It Myself*, [available on the Amazon Kindle](#), and from my blog at [Do It Myself Blog](#).

Because I was labeled non-verbal, my Grade 1 teacher, Mrs. Rutherford, was concerned she wouldn't hear me when I needed help. She gave me two of her mom's small brass dinner bells to ring to get her attention. She soon discovered the bells weren't necessary!

In Grade 3, my best friend Sandy joined Brownies, so, naturally, I also *had* to join. I kept bugging Mom until she made the necessary phone calls. After Mom had a long conversation with the Girl Guide Commissioner in our area, I enrolled in the Brownie Pack closest to our home, a welcomed change after having to cross school district boundaries to attend a school that was equipped to educate me. I was the only one with an obvious disability in the Pack, but no one seemed to notice. Mom worked closely with Brown Owl and the other Guiders to adapt the program requirements, where necessary, to ensure any changes were fair and required the same effort from me as required from the other Brownies.

One requirement for completing the Brownie program was to learn finger spelling, the alphabet used by people who are hearing impaired or deaf. This was something we learned as a Pack, and we each carried the alphabet card in our uniform pockets. I had just enough hand function to manage forming each

letter reasonably well, which was fantastic because it suddenly gave me a simple way of communicating a few words with everyone in the Pack without any cumbersome communication device. To this day, when I am orally spelling a word that someone is having difficulty understanding, I often find myself finger spelling the word as well.

When I was allowed to use a calculator in school, my parents bought a Toshiba alphanumeric calculator for me. Their thinking was that I could use it for communication when people didn't know finger spelling even if the display was limited to only eight letters at a time. Unlike other communication devices during the mid to late 1970s and even some of today's devices, the calculator was small enough to slip into my Girl Guide uniform pocket, along with a bandaid, a safety pin and a quarter for phone call. My friends enjoyed deciphering the letters as some were rather cryptic in the confined calculator space.

Several years of speech therapy served up some rather bizarre practices amongst the useful ones. For example, a therapist I had for years sat herself on a floor mat, with me lying on my back between her outstretched legs. My legs wrapped around her waist, and her stinky toes were in close proximity to my nose. She then proceeded to stick her fingers in my mouth to wiggle my lips, supposedly to loosen them. She alternated between using her fingers and ice cubes. When the speaking segment of the therapy began, she pushed on my chest in attempts to improve my breathing capacity. To this day I am convinced that several years of this hefty woman pushing down on my chest made me a very late bloomer. Not surprisingly, my pillow talk results in my clearest speech!

After the speech therapist with stinky toes, I had another for a brief time who allowed me to sit upright for the entire session. What a concept! One of the most sensible things we did was to make an alphabet card, small enough to carry with me. The simple card was to use when people didn't understand what I was saying; I would simply spell out the word on the card. Sometimes the low-tech solutions are the best ones, and I've made many variations of that card through the years.

In Grade 8, my first year at the regular high school in my neighbourhood, my guidance counselor offered to explore communication devices that might be available to me. I politely declined her offer. I had only seen one such device before. Back in the early 1980s, these devices were large, clumsy, and quite limiting.

I had just started at the local high school and I did not want yet another device that would make me different from the rest of the student body. I did not know of anyone who used such a device, instead I had only heard adults of authority telling me I needed a device to communicate. This highlights the importance of peer role modeling when encouraging individuals to use communication devices.

Fast forward to January 1<sup>st</sup>, 1988: I found myself moving into a one-bedroom apartment (with a friend for a roommate for one semester) atop of Burnaby Mountain to attend Simon Fraser University. Being in a new place where I didn't know which way was up, and where nobody understood *Glenda-ish* was a little overwhelming. My main form of communication was to use notes I had typed beforehand, trying to anticipate all the information that would be needed in that particular conversation. This took some planning and forethought! I went through several dozen pads of Post-It notes during my seven years at university. I dubbed them my talking papers.

Fast forward to 2005: I was active on the Social Planning and Research Council of British Columbia's Board of Directors, and I was beginning to give presentations. The need for effective face-to-face communication was becoming more of an issue. I began wondering whether, with the advances in technologies, there was now a communication device that suited my needs. My husband Darrell called an old friend's father who was the sales representative for a few communication devices, which he brought by our home for me to see. Despite the lure of the "shiny new objects", I wasn't overly sold on the fact that they were single-purpose devices, which would have translated into yet another big heavy item to lug around with me. And the price tag, ranging between \$4,500 and \$8,500, was definitely prohibitive.

I decided to go with a small Libretto laptop for roughly half (or less) the price and much more functionality than a single-use communication device. I used it to take notes at conferences, to give presentations, and to participate in group discussions using the free text-to-speech software, E-triloquist.

I experienced some communication success with the Libretto, and quickly added a \$15 roll-up keyboard to make typing easier. However, despite its small size, I found it clumsy for spontaneous communication. I had to unzip the laptop case, undo the Velcro straps, pull out the laptop, place it on a horizontal surface, boot it, and open the desired software before I could even begin to type out what I wanted to say. By then, of course, the conversation had progressed and my contribution was old and disjointed. The Libretto, although useful for some purposes, wasn't really convenient to facilitate communication in the way I needed. It did, however, enable me to communicate a bit more, so while it still wasn't the ideal solution for me, it was a start.

Fast forward again to April 2010. While in Chicago for a conference, I found my way to the Apple store and, after playing with an iPad for an hour, I pulled out my Visa to buy one, a month before the device was available in Canada. I also bought AssistiveWare's AAC app Proloquo2Go. Leaving the store, I had an intense feeling of buyer's remorse. Would I be able to use the touch screen reliably with my shaky and jerky movements? Would the iPad really work for communication? Would it be another fad shiny object to gather dust? Had I just put \$1,217.40 US dollars on my Visa for nothing? My stomach was in knots as I headed back to the hotel.

My buyer's remorse was short-lived. I spent an hour of quality time with my iPad in my hotel room -- enough time to unpack the thing, turn it on, and play around in Proloquo2Go and discover the onscreen keyboard and the speak button. I then met my two Deaf and hard-of-hearing friends for lunch. Typing in Proloquo2Go came in handy. A combination of lip reading, American Sign Language, and typing on the iPad, now that's AAC on the fly!

Later that night, hanging out with other friends at the bar, the iPad's back light and clear display made for easy reading in the dim light. The font size in the Proloquo2Go app was large enough to read from a comfortable distance.

The cool thing was, because the Holiday Inn and bar had WiFi, I had Internet access. When asked what I had been up to, I responded problogging and ghost writing, and I was able to show what I had been

working on, online. I also shared the video of me ziplining across Robson Square in downtown Vancouver during the Winter Olympics. The iPad allowed for a deeper level of communication that would not have been possible with a single-function AAC device.

At another point during the conference, someone was having trouble figuring out what I was saying, and she asked, "Where's your iPad?" In that moment, I felt a sense of normalcy and acceptance. Using my iPad, an iPhone in a size I can actually use is not another thing that makes me different. It wasn't using a strange, unfamiliar device to communicate with this group. People were drawn to it, because it was a recognized or known piece of technology, rather than being standoff-ish with an unknown communication device.

Even though the Proloquo2Go app has two options for communicating, the grid view and the onscreen keyboard, I used the keyboard more because of the freedom to use the words I needed without hunting for vocabulary mid-conversation. For in-depth conversations, the grid option was too limiting and too much customization is needed to add the vocabulary that I use.

In addition to using the Proloquo2Go app, I found other ways to use my iPad for communicating. Nominated for the local Entrepreneur of the Year's High Tech Award, I needed to prepare a one-minute acceptance speech in the event of being announced as the finalist. I used my text-to-speech software TextAloud on my computer to create the audio file. I then e-mailed the file as an attachment to myself on my iPad. When I was announced as the winner, the Master of Ceremonies knelt beside me and held a microphone next to my iPad. I tapped play and spoke my acceptance speech perfectly!

November, 2013, the game changed even further with AssistiveWare's release of Proloquo4Text, a solely text based AAC app. With input from several adult users of Proloquo2Go, including yours truly, the design team and programmers developed this app for children, teenagers and adults who are more literate and do not require the cutesy pictures found in many communication devices and apps.

This new technology has enabled me to birth a new dream; that of being a speaker to inspire people to raise the bar on their own life. In September, 2014, I traveled to Boston to deliver my Bold Talk, which is like a TED Talk, titled "[Go Beyond: Stare Your Fear in the Face and Boldly Go for It!](#)" to a room of approximately 500 people.

And last August, at the ISAAC Conference in Toronto, I had the honour of delivering the ISAAC 2016 Outstanding Consumer Lecture, "[Finding Your Dream, The North Star for Your Life's Journey](#)".

My capabilities are further expanded by mashing together various technologies. For example, I was asked by my friend Charlie Gilkey to be on his online talk show [The Creative Giant](#). We recorded the show in Skype. I typed my responses in the text chat, and then hit Read in my word prediction software WordQ, which spoke aloud my words. This and many other mash ups allow me to create a solution for a particular instance.

As I mentioned earlier, my inability to walk – without falling every few steps – is fairly straightforward to accommodate. However, my speech impairment is far more disabling and isolating at times, and is more complex to accommodate, depending upon the situation.

I see my speech impairment as rather fluid. With family and close friends familiar with my unique speech pattern, I need to repeat only the occasional word to be understood as if my speech impairment essentially disappears. These cherished individuals possess the magical powers of the willingness to truly listen and the desire to work to understand what I am saying.

My speech impairment becomes invisible while I am working and writing, for which I use the following tools:

- A 6-core processor computer with 4 gigs of RAM, complete with webcam, speakers and headset
- A spill-proof silicone keyboard for this redhead who eats at her desk on occasion,
- A sturdy Esterlund joystick,
- A wrist pad placed above keyboard for my hand to guide along while I type with my left thumb,
- The keyboard accessibility feature Sticky Keys available in Microsoft Office,
- The word prediction software WordQ, which speeds up typing with only my left thumb,
- The text-to-speech software TextAloud to convert my written word into the spoken word.
- And, various online communication tools (e.g., email, Facebook, Twitter, Skype).

It is when I am out and about that I run into barriers while attempting to communicate. Some people assume that I am cognitively or hearing impaired and they talk down to me, start gesturing or writing notes. Other people don't even speak with me; they talk to someone else who may be with me or they even ignore me.

My communication access requirements for telephone and face-to-face interactions include:

- My voice,
- An old-fashioned electric typewriter with keyguard for quick notes typed at home in advance of an errand; although, this has pretty much become obsolete,
- My iPad Air,
- AssistiveWare's text-to-speech app Proloquo4Text app,
- A low-tech alphabet card for back up,

- And, a trusted person, usually my husband Darrell, to make phone calls for me (e.g., to make hair and medical appointments); to assist with phone calls when I am needed on the line for security reasons (e.g., to activate a new credit card; and, to accompany me when communication is critical and when using my iPad might not be fast enough (e.g., appointment at the bank; medical appointments; trips to the ER).

The most recent addition to my communication arsenal is this stylish mount for my iPad. Initially, I wasn't keen on having anything mounted to my scooter mainly because I use my iPad in various locations – for example, while working at my desk, sitting on the couch and lazing in bed, as well as when I am out. So I didn't want it permanently fastened to my large, outdoor scooter.

Then I began realizing that by needing to pull my iPad out of my bag before I could communicate meant that I was missing out on spontaneous interactions. Yet, I didn't want to carry my iPad on my lap, particularly in some areas, for fear it would be stolen.

Around the same time, I saw my friend's Michelle's mount that rests on her lap, which appealed to me because that is where I prefer to use my iPad. I support my arm against my body while tapping.

I also saw my friend's AJ's mount on her walker. The iPad holder intrigued me. AJ kindly demonstrated how she slipped her iPad into the basket holder; I thought, I could surely manage that myself.

While wandering around the Exhibit Hall at the ISAAC Conference, I came across a mounting system that piqued my interest. The vendor assured me that he could put together a low profile mount that could swing out of my way when I got in or out of my scooter.

With a fairly clear mental picture of what I wanted and what I was pretty certain would work for me, I reached out to Tiffany at CAYA. After some tweaking, the right combination of parts was found to work on my scooter and suit my unique needs.

As I have only had the mount for a few weeks, I am still getting familiar with using it and having my iPad right at my fingertips; the ability to communicate at the ready. Being comfortable and proficient in using my iPad to communicate in spontaneous interactions will be a learning process, with trial much trial and error.

My eventual realization that a mount might be of use again highlights the importance of peer role model, even if it is at a causal, indirect way. Seeing how other individuals use their communication devices can have a greater impact than having a professional or person of authority say a piece of equipment is necessary.

As you can see, for the most part, technology has caught up with my needs and, of course, that will continue to evolve as technology changes and improves. For the most part, I have done my homework and I have what I need to effectively communicate in various situations.

However I do not possess magical powers over the attitudes and misperceptions of others, which remains the only real barrier in my communication. Some people are enlightened; they realize that my

less than perfect speech does not affect my ability to hear, to comprehend, to contribute. Thankfully I have had several key, enlightened people in my life.

But others – oh wow! – they are the unenlightened ones, living under a rock somewhere, I swear! They assume that because they don't understand my speech, that I don't understand theirs. Or, they assume I am deaf and start gestures as if an impromptu Charades has broken out. Or, they speak louder. Or, they reach for a pen and paper. Or, even worse, they dismiss and devalue me. That really hurts and is frustrating, isolating.

Before I ask if you have any questions, I'd like to mention that I have created this presentation, with many more details and information added, as a Kindle ebook, titled, *Emerging from the Cocoon of Silence: My Journey from Non-Verbal to Motivational Speaker (The Byte-Sized Version)*.

I'm happy to share the transcript from today's presentation with you. I have created a webpage just for you with the transcript available for download.

That webpage also includes several of my blog posts that you might find of particular interest. The secret webpage is at [www.doitmyselfblog.com/audi-546/](http://www.doitmyselfblog.com/audi-546/). This URL is also on my handout, which, I believe, is available on the course site.

For questions, I am happy to answer questions requiring relatively short responses. For questions requiring longer responses, feel free to email me.

I would like to wish you success in your future career. You will be in a position to assist people with using their voice, whether it be their natural voice, a device, another means of communicating or a combination of methods, which can be quite freeing, liberating and empowering.

All of the best to you. Thank you.

### **Let's connect**

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