



GIVING VOICE TO THE VOICELESS

Parisa
Khosravi

Earlier this year I gave a TEDx talk on a very personal topic. It was the hardest speech I had ever had to write and present.

Our intention in sharing our story was to help others, open hearts and minds, and change perceptions about autism.

Here is that speech and what has happened since...

I was a journalist for nearly three decades. My joy and passion in journalism was giving voice to the voiceless.

The irony was that at home I had a much tougher responsibility... my kind and gentle son had no "voice."

At work, as the head of international newsgathering for CNN, I had a very different criteria for measuring my achievements, such as: meeting with Popes and Presidents, or ensuring that our teams safely reported from war zones like Syria and Iraq... even diverting a commercial airliner in order to get our people to a breaking news event.

I directed the coverage of countless historic events including the earthquake in Haiti, the tsunami in Japan, the Arab Spring, and throughout the years received numerous prestigious journalism awards.

3am calls were what I was used to, and sometimes even initiated them myself in order to get an update or check on the safety and status of our journalists working in warzones and hostile environments. In fact, I cared so deeply for my colleagues' safety and well being that one of their nicknames for me was Mother Parisa.



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Giving Voice to the Voiceless
Parisa Khosravi

Yet, at home, being a mother felt like the the most challenging responsibility I had ever had.

Maybe it is not proper to say such a thing, but it was true for me.

As a first time mom, I was not sure what to expect, and kept hearing that it gets easier as they grow older. “Their sleep gets better and they start talking and you will know what they need...”



This was not the case for us. My son, Payam, would be up and awake for most of the night.

At around the age of two my playful and active child started disengaging.

My son was diagnosed on the autism spectrum just before his third birthday.

It was such an out of body experience when I heard the diagnosis.

After telling us the results the doctor gave me a piece of paper with the list of three therapists for my son. It's odd how certain images stay with us. That piece of paper was carelessly copied at an angle, so the list was slanted on the page.

It was such an appropriate metaphor for how different it was only about a dozen years ago. *There were so few available resources*, that the messy copy of a list of three specialists, was the best and only thing this top notch developmental pediatrician from a very respected medical center could offer me.

I didn't know what to do next, there is no road map, each child is different and results vary with each therapy. There was no time to grieve, every day counts, early intervention is key. I guess I went into a full journalist mode, and started searching for answers.

We tried everything. I mean everything. I had at times 20-30 therapists and teachers come to the house every week.

At the age of five, nearly two years of intense hard work and behavioral therapies went down the drain when we tried a new and somewhat unconventional method of therapy which had a completely negative impact and resulted in Payam essentially being overwhelmed by sensory stimulation. As you can imagine, this experience made me very apprehensive and cautious in trying newer methods and therapies.

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At home, just as in my career, I was relentless in pursuit of answers and results.

I made sure Payam was nourished with a healthy diet, exposed to continual learning and all types of activities... hoping and preparing him to reach his full potential, whatever that potential may be.

As the years passed, Payam attended private school and was home schooled, was exposed to travel and the news (you can imagine the news was always on in our house). He also had endless hours of educational therapies, including music, speech, occupational therapy, swimming, horseback riding, and many many more. You name it, he has done it.

He is the hardest working person I know.

Throughout, Payam was only able to communicate in the most basic manner with a few simple words, expressing his very basic needs—leaving us to wonder what he was feeling and thinking, and how much he actually understood from all that we were teaching him.

I kept my eyes open for any new methods of communication, but also remained very cautious.

Incidentally, a few years back, I had heard about RPM, Rapid Prompting Method, which essentially helps those who are non-verbal or non-reliable speakers to communicate by spelling out their thoughts letter by letter, on an alphabet board.

As I looked into it, I got concerned about the experts' reviews that this method was not legitimate and that it was not really the kids who were spelling, but rather their teachers were moving the board and spelling for them.

I was worried about regression again, and did not pursue RPM based on what I was hearing from the experts.

It's interesting how life works, this past year I happened to talk to two moms, in different parts of the country, just a few weeks apart, it was like serendipity, and they both talked about their kids' great success with RPM.

Throughout all these years, I have learned that the best source of information are other parents with similar challenges, and what I was reading and hearing from many of them regarding this method was fascinating. I also attended a workshop and watched kids communicate by spelling on the alphabet board.

There are stages in RPM, using different types of alphabet boards: stencil boards, laminate boards and eventually keyboards.

I made an appointment with an excellent experienced teacher in this method. She treated Payam like a typical kid, and presumed that he is fully competent.

From the very first session, Payam showed us that he completely comprehended each lesson that was read to him, and started answering related questions via the letter board. I couldn't believe my own eyes. Here was my fourteen year old who had barely been able to communicate for all these years, and finally, FINALLY we were getting a glimpse inside his thoughts.

But my skeptic journalist mind *kept questioning* the fact that he was actually spelling out the answers. I kept going back to his sessions, week after week. I had to double check, triple check, and quadruple check as he wrote on the board. I watched in disbelief as Payam understood every topic read to him, ranging from 3D printers to how the brain works to Gandhi's philosophy and the aurora lights.

I observed him for eight weeks, eight sessions, talked to other moms and read an incredible book called *Ido in Autismland*.

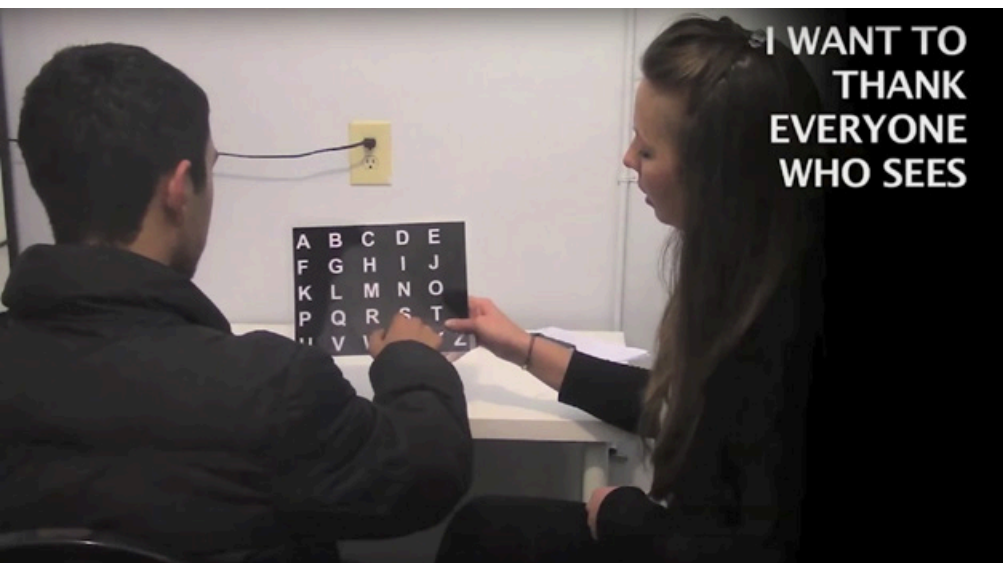
At last, finally, I believed.

For so many years, we had tried so many different methods and therapies, gone to each one with such high hopes, I think I was just afraid that it was too good to be true and was managing my own expectations and perceptions.

PERCEPTIONS!

Here was my fourteen year old who had barely been able to communicate for all these years, and finally, FINALLY we were getting a glimpse inside his thoughts.

During my [TedX Talk](#), I showed a clip of Payam with his teacher, so that the audience can better visualize what it looks like.



And for the purpose of making it easier for the audience to follow what he was writing, the letters he touched on the board were shown on the right side of the screen.

Payam has to work so hard to control his body and eye movements as he writes. It is a serious challenge of his fine motor and gross motor skills. His teacher transcribes what he is writing, so that we can keep up with him and also have a record of each lesson afterwards.

He is wise beyond his years, even if from the outside you might have a different perception. Below is Payam's full message written on the alphabet board, it took about five minutes for him to spell it out letter by letter:

"I WANT TO THANK EVERYONE WHO SEES THIS AND BEGINS TO SHIFT THEIR PERSPECTIVE TO HAVE MORE BELIEF IN ALL OF HUMANITY."

How many times have we been told not to judge a book by its cover? How often do we fail and completely judge others based on what we think is "normal" or acceptable? How do we know what they are thinking or feeling, if they are not able to tell us in the ways that we are used to? Why do we presume to know their cognitive levels or what they will be capable of in life? Who are we to judge?

His name, Payam, actually means “message” in Farsi, in Persian. He is my heavenly message. He has been my ultimate teacher in life.

I remember, early on after his diagnosis, he was playing in the backyard, and as I was watching him it just came to me. Not, *why me?* Not, *why my son?* Instead, I thought, *wow, me!* Payam has chosen me to be his mom. I did not know why he had picked me, I just felt this incredible honor that I get to experience life with a very special son.

I have always described Payam as walking love and my little Buddha. Not so little anymore though—he towers over me. He teaches me about patience every day and forces me to be in the present.

Now through his letter board, Payam regularly writes about helping other non-speakers and wants them to know about this tool and method of communication.

He wants schools and teachers to always presume competence and know that just because some students are not behaving or responding in a “typical” manner... this is not an indication of their cognitive level.

He recently wrote:

“I THINK CHALLENGING THE VIEWERS TO FREE THEIR MINDS OF ALL PRECONCEIVED IDEAS ABOUT NON SPEAKERS IS IMPORTANT TO PERCEIVING US AS CAPABLE LEARNERS.”

He cares so much about spreading this message that when I was invited to do this talk, I asked him if he wanted me to speak about it at this setting.

I have deep respect for Payam's privacy and I was frankly very reluctant about sharing his story so publicly. This is what he wrote in response to my concerns:

"I THINK THIS TED EVENT AND AUTISM NEED EACH OTHER. HELPING OTHERS IS MY PRIORITY. A LOT OF PEOPLE WILL LEARN FROM MY EXPERIENCE WITH LEARNING TO COMMUNICATE USING THESE TOOLS.

MOM EXPRESSES HERSELF SO WELL. I TRUST SHE IS THE RIGHT PERSON FOR THE JOB."

When I pressed him on the privacy issue, he added:

"MY STORY NEEDS TO BE HEARD. HAPPY FOR YOU TO SHARE."

How poetic that my son gives me permission, and in the process is the one who helps me find my voice for the first time to share this emotional journey and personal quest.

I did not know why he had picked me,
I just felt this incredible honor that I get
to experience life with a very special son.

Getting to know my son, his thoughts, aspirations, sense of humor, and a deeper insight and understanding into all the challenges which he continues to face and deal with on a daily basis, leaves me in awe of him and humbles me beyond any words I can say to you.

You know that 8th lesson which finally got me to believe... it was about geysers at Yellowstone. Payam picked the lesson on geysers out of three other options. The lesson partly talked about Old Faithful and how often it erupts.

His teacher then asked him some related questions, tapping into his general knowledge... she asked him “what does predictable mean?”

Payam wrote:

“IT MEANS THAT I AM SOMEONE YOU CAN COUNT ON.”

She then asked him what’s predictable about you and he wrote:

“I AM A LOYAL FRIEND.”

At the end of the lesson his teacher asked him to write about what makes him erupt?

This is what Payam wrote:

“CENTURIES OF DISCRIMINATION HAVE CREATED GEYSERS OF HATE AND INTOLERANCE. THESE ACTS ERUPT AND HURT THE CHILDREN OF THE WORLD NEEDLESSLY. TEACHING ACCEPTANCE IS MY LIFE’S WORK.”

After seeing him write those words, both his teacher and I were in tears, Payam wiped his own tears as he finished writing this message.

Later on that evening, I sat down with Payam and apologized to him for all the frustrations he must have experienced throughout the years and also my own recent skepticism.

He listened to me quietly and then simply moved over and gave me a kiss on the cheek. That kind gesture told me everything I needed to hear.

For all these years, his voice has been trapped in his body, and he has had to reconcile with that fact. Finally, a window has opened up for him to express himself and be able to share his empathy and compassion for others.

He has been observing everyone and everything all along, and is now finding the power of his voice and sharing his message, *his Payam* with the world.

He too has a deep passion for giving voice to the voiceless—regardless of the reason for their silence, be it disability, society, or self imposed. Payam uses his letter board to share the power of his voice and advocate for others.

At different points in our lives, most of us have silenced our own voice at home, at school, at work or in our communities. Why do we do that? And what is *your* metaphoric letter board that you can use to find the power of your voice?

When I finished the talk and walked off the stage, I wanted to know how Payam was feeling. He had watched the rehearsal the night before and of course had heard me practice a number of times prior to the big day. However, the morning of the talk when I asked Payam if he wanted

to be in the auditorium while I gave the talk, he wrote on the board that he wanted to be in the room while the other speakers gave their talks and would then leave when it was my turn.

I was one of the last speakers, and when my turn came up, his teacher who was with us had again checked with him if he wanted to stay or leave. Payam had changed his mind and decided to stay, and I am so thankful that he had. For him to see and experience first hand the reaction of the audience and the feeling in the room was incredibly special. I was told there was not a dry eye in the house, and Payam got to witness that himself and then felt the audience's appreciation of his words by watching them give our talk a standing ovation.

Besides the talk, our plan during our trip to Big Sky was to go and visit Yellowstone and see the geysers. On a beautiful sunny winter day we saw the park and watched Old Faithful erupt with all its might. That lesson on geysers about nine months earlier was such a turning point for us.

At different points in our lives, most of us have silenced our own voice at home, at school, at work or in our communities. Why do we do that? And what is your metaphoric letter board?

The talk was posted online about a month later, it was a big day for Payam and he wrote the following thoughts to his teacher:

“JESS I AM READY TO ENJOY THIS MOMENT OF GRATITUDE WITH YOU. RIGHT NOW I AM OVERWHELMED WITH EMOTION SINCE EVERYONE HAS BEEN ABLE TO SEE THE TED TALK AND MY STORY. THANK YOU FOR SUPPORTING ME TO DO THIS. EVERYONE DESERVES TO HAVE THE SAME OPPORTUNITIES MY GOOD FORTUNE HAS GRANTED ME. DESERVING THE WORLD SHOULD NOT BE GRANTED TO ONLY THOSE WITH RESOURCES, BUT INSTEAD TO EVERY PERSON THAT EXISTS.”

He continues to inspire me with his level of empathy and compassion and how he advocates for others at every opportunity.

Payam has now advanced from the alphabet boards to typing on the key board, and has recently been asked to give a presentation at a conference at GA Tech about sensory movement differences. He has accepted and is now writing his speech on a key board.

He has titled his presentation: “Rethinking Autism and Therapeutic Approaches.”

Payam has asked me to be his voice and read out his speech to the audience at GA Tech. But I have a bigger dream for him and other non speakers or unreliable speakers.

By the way, you might wonder why I refer to them as non speaking rather than non verbal. Non verbal implies no words, they have words and the language, they just don't have speech, it is a motor challenge or as Payam calls it “a mouth that disobeys.” Interestingly enough, we know and accept this challenge of a mouth that disobeys to be the case for many stroke victims.

I know technology will close the gap one day for those who have minimal speech and sounds or the unreliable speakers who can spell their thoughts. So instead of a robotic or generic computer voice reading out their words, one day their own voice can be programmed and heard via the computer. I am working with different technology companies to make this a reality. Giving voice to the voiceless was my passion and joy in journalism. My goal now is to help literally give voice to the voiceless for the non-speaking community. Or as Payam calls them the “silent champions.”

I am often asked how Payam has changed since he has been able to communicate after all these years? The thing is, he has not changed, I have changed!

Of course he is happy about the fact that we now know that he fully comprehends everything.

However, I am the one who has shifted the most and continue to adjust. At times I still catch myself repeating a phrase or a question to him, sometimes momentarily forgetting that he understood me perfectly the first time I said it. Or I catch myself simplifying my sentences and then remember that his vocabulary and writings are stronger than mine. I have to break my own old habits and loops. It is easier said than done.

What we have changed since last year is the level and variety of academic exposure. Payam’s dad reads a variety of books to him every night, from the *Alchemist* to *Positive Intelligence*, *The Power of Difference* to the history of Cyrus the Great in *Discovering Cyrus*. Payam enjoys knowing more about other individuals on the spectrum and their perspectives, he likes history and science. He has a wonderful math teacher and he has asked her to teach him about complex theories. Payam is a brilliant chess player and solves expert level solitaire chess within a couple of seconds.

I can only imagine how bored Payam must have been for all those years as he was taught simple math or reading books way below his cognitive level.

Payam now regularly writes about humanity, equality, and acceptance. Here is a recent writing by Payam:

“MY DREAM IS FOR THE ENTIRE WORLD TO ABOLISH THE PAIN THOSE EXPERIENCE FROM UNNECESSARY JUDGMENTS BECAUSE OF EACH PERSONS UNIQUE DIFFERENCES.

PEOPLE NEED TO RECOGNIZE HOW THEIR ATTITUDES ARE NEGATIVELY IMPACTING OUR GROWTH FOR HUMANITY AS A WHOLE.”

This message from my teenage son on the autism spectrum who communicates via an alphabet board and key board.

A great reminder to all of us that we never know what is inside someone until we give them a chance. 🙏



Info

About the author

Parisa Khosravi is a respected veteran journalist and executive with three decades of experience in global media. As a CNN senior executive, Parisa directed coverage of countless award-winning historic news events, helped build an internationally diverse and multi-cultural news division, and skillfully opened doors and gained access for CNN journalists around the world. During her tenure with the company, Parisa led international and domestic news gathering, was responsible for 45 bureaus and more than 100 correspondents, as well as a large behind-the-scenes staff around the world. AS a recipient of numerous top journalism awards, such as the Edward R. Murrow Award, the Peabody Award, and the Emmy Award, Parisa has been recognized for her in-depth expertise in international and geopolitical affairs, cultural diversity/competency, and crisis and risk management. Parisa is active on the speakers circuit and is a consultant to private and Fortune 500 companies.

You can watch a video of her TedX talk on [The Power of Finding Your Voice](#) online.

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