SAVED BY TYPING

An Amazing Autism Story

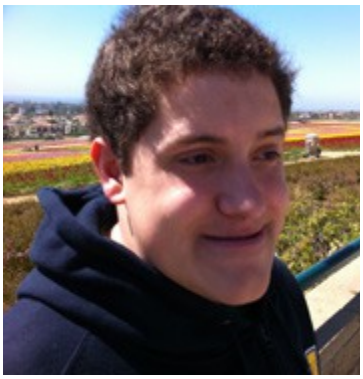
by John Smyth



Finding a Voice
in a World of Silence

For us, no typing = no communication

An Amazing Autism Story



Hi. My name is John Smyth. I am 19 ½ years old and have autism. My autism is so severe that I often cannot talk. My mind tells me what to say, but my lips will say nothing or make sounds I do not intend. So I type with one finger to talk, with some support from my dad, aide at school, brother, or others in my life.

Some people say that my communications are not real. I just ask you to come to one of our monthly Saved By Typing meetings to see how real it is, meet new people whose voices have recently been discovered, or visit the Evidence tab of www.SavedByTyping.com.

Pending publication of my books, my short story until winter 2012 is shared for your understanding. My life and my story involves school systems. To avoid unnecessary negative politics, I do not use school names. Instead, my old school is The Rich School. The Caring School is where any school education has happened for me in the last two years. Here is my short story.

For 16 ½ years, I had no way to communicate with my family, doctors, teachers or others. As I will explain, I believe the way was always there, but no one was educated or cared to try it. What is amazing about my story is not that I can now communicate with you and answer your questions afterward, but that I am the first person among all the dozens and possibly hundreds of nonverbal autistic persons ever to be in The Rich School District who can now do this. And I can do it because I go to The Caring High School. I'll share that story with you.

There are 3 things I want to tell you about today:

1. I want to help you know what it was like for me when autism came. I'm going to share the lonely world many of us live in today.
2. I'm going to share some of my discoveries in the Landmark Forum and what they mean to you and me.
3. I'm going to share what is happening for me now and ask you to help others like me to do the same thing. I'll provide specific suggestions for that.

When Autism Came

The way autism happened for me was slowly. When I was little, I remember that wanting things when I did was harder and harder to communicate. All ways to call were affected. Sometimes really looking was hard. When I wanted to approach, my eyes wouldn't work to focus. I was very exasperated and wanted to tell all around me and words would never come out. When all others were speaking, I would understand but my body would not cooperate and would do things autistic-like, such as awful acts to hurt myself, standing around on high furniture and jumping, and really eating anything anyplace, anytime.

Even though I knew the language, I couldn’t share what was happening. The way out was not clear. I believe my ability to type existed starting at age 3, when I read a dictionary and realized what it was- the key to our language. From there, I was self-taught to read. I have probably a greater interest in others than most, maybe because of my dysfunctions. Everyone who is challenged is motivated in the same way.

Angels



My brother David has been my Angel for as long as I can remember.

There were Angels in my life along the way. From as far back as I can remember in the crib until age 4, I will always remember that my brother David was wonderful about praying for me. When I was not feeling well, David would come to my crib to cheer me up. He also assured me that I was not alone and he was with me. He was wonderfully comforting with all quite painful and confusing autism.

Between the ages of 4 and 8, the caregivers who worked with and believed in me were angels in my life. When autism masks who you are as a person, waiting and watching for those who will believe in you and take you to new levels of learning is sometimes lonely and painful. I admire the dedication of those who sometimes couldn't see the progress and reasoned to teach anyway. All along, I was learning.

From 8 to 12 years of age, the wonderful kids who endure disabilities without complaining and who have no voice often but are competent became special to me. I admire their heart for the moments they are in, their patience with the people who unfairly judge them, and their sacrifice for all apparently well people who need the sick and disabled to realize that their time will come and some human qualities can’t be developed except through suffering together. All wonderful persons still waiting for a voice are my special heroes.

Between ages 12 and16, my aide Jane at The Rich Middle School saw me for who I am and incredibly taught me when everyone else said I was stupid in their 'special' way. Through Jane I came to realize that I could smartly acquire information and apply it to understand the larger world around me. Civics, sports, and politics assumed more importance in my thinking. Science assumed new depth and breadth. Without Jane, I would not have as much confidence.

At 16 ½, on December 9, 2010, I met Laura Poorman. Really I admire her selfless heart for wanting patients like me waiting for the gift of language. She is the doctor of language who diagnoses if she can help and then treats the soul or body equally as healing from a dark, cold place begins. She waits to let only enough light in that the patient's eyes can handle. She always gives of her extraordinary ability without saying she is too tired or in pain. We who are healed by her touch are eternally grateful.

Discoveries From the Landmark Forum

The following expresses my experience in isolation, including all of the years in The Rich School District and especially my 2 years in The Rich High School. I share this for those still there and those to come behind them. I believe this is the experience of most nonverbal autistic persons in The Rich School District and some other schools. Please put yourself in my place and hear my words:

> "THE AUTISM SHOWED UP WHEN I WAS LITTLE. IT STOPPED ME FROM COMMUNICATING AND BEING IN RELATIONSHIP. THE STORY DOMINATED MY LIFE. IT WAS HOW I WAS INTRODUCED, HOW I CAME TO ALWAYS ACT AND PARTICIPATE. EXCEPT WHEN I WAS SLEEPING, I WAS TREATED AS NOT

PRESENT."

I remember the sad time in Lifeskills, waiting for someone and REALLY SEEING THAT THEY WOULD NEVER COME AND FIND ME, REALIZING I WAS TRAPPED IN A BODY THAT WAS A TOMB, TOTALLY REAFFIRMING AND POISONING ALL SADNESS INTO DESPAIR.

RELATIONSHIPS WHERE PEOPLE JUST STARED OR LOOKED AWAY REINFORCED THE HOPELESS TRAP EACH DAY BECAME. QUESTIONS ABOUT WHEN BECAME FAIRY TALES OF SHAME AND PRISONS OF THOUGHT. WAS ANYONE EVER GOING TO KNOW I WAS HERE OR WOULD IT ALWAYS BE LIKE THIS?"

THE ALWAYS ALREADY LISTENING WAS THAT I DIDN'T KNOW WHAT WAS HAPPENING AND TEACHERS REALLY DIDN'T KNOW I WAS ANGRY, SAD, ALWAYS WANTING HELP, ALWAYS TRAPPED AND GETTING LONELIER AND LONELIER. ALL ABILITY TO SLEEP AND TALK AND LEARN WAS STOPPED. I WANTED TO TALK TO ALL I HAD IN MY LIFE BUT THE WORDS WOULD NOT COME. AUTISTIC ACTIONS MASKED MY BEHAVIOR AND I AM AFRAID. IT IS HOPELESS TO GET RID OF THE AUTISM. THE WAY FREE IS DARK."

Now, let me change the perspective. On January 29, 2012, in the Landmark Forum, I typed:

Today was an incredible day. After a particularly grueling period when people of every age and race spoke about concerns with the same things that I deal with, such as family relationships, love, security, and expressions of relatedness, I noticed that I am the same as everyone else. Really, my struggle with autism as a prison is nothing compared with the prison of my identity, the limitations, beliefs, and restrictions that I transparently put on myself that channel my outlook. These artificial creations of my mind empower or disable me far more than my autistic struggles. Everyone is in the same boat as me and we think we're alone. From now on I am creating a life of RELATIONSHIP, POWER, POTENTIAL, AND MAGNIFICENT EXPERIENCES.

YES, THE FUTURE IS WHAT I MAKE OF IT. REALLY, GOOD EXPERIENCES WITH REALLY GREAT PEOPLE FILL MY FUTURE….

What was the reason for this change?

I learned that "happening" is different from "interpretation". For the most part, our expression of self is a story in a story. I see that we look at the easy things and make ourselves "autistic" and it’s a lie. The science is a story too. I am "me" with my story and you are "you" with your story. This utterly traumatic taking life and throwing it out the window by intelligence testers and teachers who don’t believe really reeks. I’m so much more than that and so are most autistic people.

I was misdiagnosed as unintelligent after being tested unfairly. That is someone else’s story about me. The test protocols are like asking a blind person to answer written questions and grading them "mentally incompetent" and "low intelligence" when they can't see. These protocols have to change.

By labeling me this way, no one had a responsibility to "find me." Experts are throwing people’s lives away every year. I don’t know about other school systems, but I know from the Special Ed Department Head at The Rich High School that no one has ever escaped the The Rich School Special Ed gulag

once they were assigned to it. That remains true today. For someone, by sharing our work, you may change their world.

In Landmark, I discovered that:

> WE ISOLATE OURSELVES AND DON'T PARTICIPATE IN THE AMAZING OASIS OF PEACE THAT ALWAYS COMES FROM CONTRIBUTING. WE REALLY NEED POWERFULLY WORK IN OUR LIVES TO AWESOMELY USE OURSELVES FOR OTHERS. WHEN WE DO THAT, WE APPEAR POWERFULLY DIFFERENT TO OURSELVES AND OTHERS.
>
> RATING THE POSSIBILITIES ON A SCALE OF ONE TO TEN, I AM NOW A 90 AND CLIMBING. REALLY, LIFE IS TOTALLY TRANSFORMED AND I WILLFULLY ENGAGE AT EVERY LEVEL AND POWERFULLY ENGAGE WITH MYSELF TO DO THAT. AND I AM FULLY COMMITTED TO REACHING BACK TO THOSE I LEFT IN THE DESOLATION OF ISOLATION, WHEREVER THEY ARE. BRINGING THEM INTO THIS PLACE OF POSSIBILITY OF WONDERFUL PARTICIPATION IS MY AWESOME PURPOSE.

Imagine that now you are 60 years old and the way free is still dark. You have still never communicated with anyone. And no one has a responsibility or care to come and "find you". What will God say to your fellow citizens who could have helped you out of the ditch? I'm asking you to help me find those people.

Here are my immediate projects after the Landmark Forum:

1. To type independently and, if possible, to speak.
2. To get a high school diploma.
3. To help others get a voice by the Saved by Typing program I started.
4. To speak and write for change to Indiana's laws and educational assessments and protocols for teaching the nonverbal.

What is Happening for Me Now

I am practicing the independent typing every day. I can type on my own to copy text and sometimes to answer basic questions. I often speak those basic answers faster than I type them.

I speak to you now because my family moved to The Caring School District. My dad received an opportunity to service new clients in The Caring School District area. It seemed providential that we should make a move there, where the school officials might give me a chance for an education.

- I had to start with no credits because The Rich School wouldn't give me any, and with no benefit of the doubt, because The Rich School wouldn't give me that.
- After 6 weeks, I tested out of 7th and 8th grade Math even though I never had a math course. In The Rich School until I was 17 years old, I never had the opportunity to learn anything beyond ABCs, telling the time, and basic ideas. I was more committed to learning than they were to teaching.
- Once I entered high school, my parents believed what The Rich School told them about me having no educational potential.
- Last year (2011) I dug myself out of Life Skills and the extreme difficulty of switching school systems.
- I earned an A in Algebra I and several other high grades and presently have a 3.545 GPA.

- I began this school year with an A in Geometry and am now on a regular diploma track, which The Rich School denied to me.
- The Rich School would not even teach me multiplication or give me the opportunity to even take a computer math course because they said I was "not able" to do math.
- Yesterday I received word that I tested out of the English 10 course by a wide margin on the State End of Course Assessment exam. I had never had the course.

Except for my time in The Caring School District, I am entirely self-taught. Awesome schools like The Caring Schools want everyone to succeed, not just the perfect. My home room and geography teacher, Mr. Smith, told my Dad the following when he said I would be with you this morning:

> "That is outstanding!! It sounds like an awesome opportunity for him..... He is doing wonderful in my class. In fact, he hasn't even missed a point on any assignment. Just today, he got a 15/15 on a quiz. I am just glad that he is happy and engaged. More recently we have done sort of an altered "debate" with the class and he has done a great job speaking his mind and formulating educated and timely arguments."

My friends, I always had this potential. It is not amazing that you hear this story, but that you haven't heard it a great deal more. The Rich School may be like many other misinformed schools. I do not attack them, but share personally my experience and advocate for those they mistreat.

We are not unintelligent observers of our social issues, either. The following is my December 2012 response to my brother after reading his blog about the Newtown, Ct. tragedy that was partially blamed on autism:

> Autism makes your body do things your mind doesn't want. There was no autism in this real tragedy. Always there is walking with each way quietly in wonder or aloneness. We always confuse what quietly happens with the interpretation we say is true. Wasting amounts of all emotion and some amounts of interpretation based in assumptions about the world founded in worldview choices we awfully created a life's wasted argument ago serves none except those who would imprison us with more laws. Healing would involve spending the time and energy otherwise devoted to gun control on mental health services. All will say we are all about caring. Each will talk and so few will connect with love and caring.

Really, the prison of isolation gets awfully more real as we apply laws and prison authority on politicians ever more isolated from real life. Their careers separate them and our interests and that this change is critical. Assuming that amazingly could happen, we still will need to address real work more each day walking with each other. When this happens and we stop adding all kinds of burdens on each citizen's shoulders, we can all begin to heal. Whether you agree with my thoughts or not, neither myself nor my other intelligent autistic friends still trapped in isolation have perspectives to contribute.

My summer and fall of 2011 were miserable. I was outraged that The Rich School would not hear my voice and made me move from my community to have a voice and get an education. I am so thankful that The Caring School District cared enough to listen and be open to believe.

In November of last year, I wrote the following about Great Teachers and Teaching:

> Really, what leads the student is the teacher's belief in the student. The teacher provides the powerful listening that makes great thinking possible. Teachers who have no confidence to do this or in themselves steal the educational POTENTIAL OF THE STUDENT, WHETHER THEY ARE PARENTS, EDUCATORS IN A SCHOOL SYSTEM, OR

> SEMINAR LEADERS. THE MAJESTY OF GREATNESS IN a teacher is silently hidden in their awesome commitment and belief in the great potential of their students.
>
> I don't know a lot about communicating and writing to believe in another, and there will seemingly be few who are able with confidence to ensure the sound understanding of another. I do know that my experience with knowledge acquisition is that belief in the learner always allows a massively better resilience in the learner's relationship with the information. And when it comes to waking up great and lasting learning capacity, only the belief and confidence of the educator surpasses all.

I ask you to help my friends whom The Rich School will not listen to and believe in to reach and teach, and those now out of The Rich School system who still do not have a voice. My friend Todd Washburne in Vermont had no voice until he was discovered at age 39, 7 years ago. Many people who are discovered eventually come to speak and type independently.

Saved By Typing

Last August my typing friends and I began an organization I call *Saved by Typing*. On the 3rd Saturday of every month, we get together in a conference room at 116th and Meridian to celebrate being together while typing to communicate with each other. Admission is free but you need to contact us in advance so we have free food for you and your guests.

We share our lives and answer questions to open the possibilities for other nonverbals. It is great fun for us to see each other, and we invite other nonverbals and their parents, doctors, aides, teachers and you, the general public, to see how real our communication is.

This past Tuesday night, a 13 year old boy who has never communicated typed, "Hi Mom. I love you". It was his first communication. He has a voice because of our work and caring people like you who take the time to spread the word.

My Book

Also, if you like my story, please read my first book when it comes out soon and write a nice review if you like it. Please give me your email for this by making it OK to share your information with Mr. Cotton.

We autistic nonverbals see, smell and hear things differently, and we have something to contribute.

Here is My Case for Action

It is estimated that 110,000 people nationwide, including a number of severely autistic children and young adults like myself, are trapped in unresponsive bodies. Being trapped, we are unable to communicate without a trained expert to discover us. Our parents can't know our voices, love, level of intelligence, or how to help us best. Our doctors have to guess about care because there is no way to understand from us what is working or any side effects. We can't communicate with brothers or sisters. Without communication, we can't explain why we behave in certain ways or what we are experiencing.

For me, it was like being buried alive for 16 1/2 years. The isolation was terrible. I know many more kids over the years whom I believe are still in the same circumstances that, only by grace, I …escaped.

I and others like me were rated as low intelligence and placed on dead end tracks because educators usually can't communicate with us. Yet, because we are often extremely bright, we have contributions

to make to our families and communities that are being lost while we die inside of boredom, desperation and loneliness.

If this continues, many will never share their special, God-given voice. Our families and caregivers will never know the love and appreciation we felt, our intelligence will never have a chance to contribute to a different perspective, and society will have far higher than necessary costs of care over our lifetimes because of our complete dependency.

This terribly desperate situation is also a huge opportunity for you and I individually to give someone their life back, and to give parents their children back. For me, I got my parents back at a whole new level the moment I could communicate, tell them that I love them, and that I was desperate to communicate all of those years in isolation. Getting my family back was priceless, and I am forever grateful. Fortunately, the woman who discovered me is still in Carmel and loves helping others.

In Conclusion

In conclusion, WE ARE HERE TOGETHER. WE ARE NOT SEPARATE BUT ARE CUT FROM THE SAME CLOTH. WE ALL WANT TO CONTRIBUTE AND ONLY NEED A CHANCE. We want others who cannot speak to open their wonderful will to the new late-arriving possibility that they matter.

My experience is that they waste in the ignorance that reality has supported that they do not matter. We are powerfully talking about a new reality for someone who has never communicated before. When we open the possibility that they do, all worlds around them shift. Life is newly created, love and gratitude can be expressed, and perhaps ideas that could not be known are shared. We are all enriched.

To give someone this voice is amazing. Wanting to make a difference finds its fulfillment in the wonderful moments of newly discovered speech and intelligence. We are renewed in our own personal importance. When that voice speaks, it can renew itself to God and its family. Real experience can be known. Wanting each day from a place of hopeless isolation ends. Wonderful joy in hearts is overflowing.

A Call to Action

Here are 6 Specific suggestions I have for you:

1. We need Rich School District Boards to take responsibility for their atrocious denial of people's voices over the years.
2. We preciously need to seek out those who want an opportunity to speak and inspire courage to come out, including those who have graduated from the gulag.
3. We need to train teachers to test more ways to communicate, including typing, and while assuming competence.
4. We need to understand that intelligence tests of the nonverbal are often measures of inability to communicate, especially for persons with autism.
5. We need To TEACH WHAT WILL INSPIRE A PERSON WHO ONLY BELIEVES THEY DO NOT COUNT.
6. We need you to come to Saved by Typing and bring all you can- TEACHERS, HELPERs, PARENTS, AND NONVERBAL KIDS TO EXPERIENCE US TOGETHER and see how real the life is that you can give. Your cost of admission is only that you care enough to help find the lost and isolated.

Join me in seeking out these truly abandoned souls in our community. Give them, by grace and your

personal attention, each day for the rest of your life and theirs, a quiet peace that God heard their prayers, and thanks to Him for you.

We owe it to our own families to lift others up. Those who have much really are expected to give in equal portion. If God cares for you, you must care for them. Tell them every possible way that you can. The final way for all of us is one of mutual respect and peace.

Thank you.

John Smyth
December 2013