

February 9, 2013

Hi Samantha,

I want to thank you for your patience. Typically I would site a busy schedule to explain my delayed response. It has been busy, but to be honest I found your questions interesting. I had to give my answers some thought. I was also in the process of organizing my office. I was knee deep in old files, throwing out papers and documents long past their 'use by' date. Among them I discovered a career journal that I kept, with entries beginning in the summer of 1976 when I interviewed for my first teaching position with Jenison Public Schools (JPS), in Jenison, Michigan, through the last day of school in June of 1978. I have the first years of my career documented in detail. I worked for JPS for 20 years.

As I read through the journal I realized it would have a direct impact on my answers to your questions. Time has a tendency to sand off the pointed edges of some of life's experiences. It allows us to look back and laugh at ourselves, replacing that which is unfavorable with the forgiving twist of our memory. Unfortunately, the journal from my first days as a teacher doesn't allow me that luxury. I am answering your questions on my computer, with the typewritten pages of my journal scattered on the desk next to me. They are keeping me accurate and accountable to my experiences with autism in the mid-1970s.

The replacement of typewriters with computers is one of countless unforeseen changes in the last 35 years. For my purposes in answering your questions, it will be important for you to consider context. When I began teaching with four children with autism in 1976, people were enthusiastically wearing polyester leisure suits and watching the sitcom Laverne & Shirley. The '@' symbol was rarely used, and never used in reference to an address. There was very little information about autism available. And, of course, no Google searches to help sketch my direction. The words we used were different. Only children with severe or 'classic' autism were being diagnosed. The 'autistic children' of 1976 were diagnosed with a low-incidence developmental disability. They are referred to as 'children with autism' today, and are being diagnosed in ever-increasing numbers that include a wide range of severity and ability. Communication between teacher and parent was different, reliant on landline telephones and hand written notes. As I refer to my journal to help me answer your questions, please keep in mind that life in general, and our understanding of autism has dramatically changed on many fronts from 1976 to today.

Before I get started, I need to share a few random and unrelated thoughts with you that don't belong in the same paragraph. I am very impressed with your school! I think it is awesome that you must complete a yearlong senior project. I want to thank you, too, for allowing me to share your letter, photo, and my answers to your questions with others. I have slightly revised the order of your questions. Please note, too, that all proper names of my students, parents, and colleagues have been changed to keep their identities confidential.

Question #1: What inspired you to choose your career?

After college, my first job was as a teacher at a Head Start preschool program. One of my students, David, had unique responses to many activities and situations. I will never forget him. He had difficulty interacting with me, my assistant, and the other children. Changes or setbacks that seemed inconsequential to me could emotionally de-rail David. Beginning early in the school year, I made several requests to the county services for assistance. In spring of the following year, David was diagnosed as a child with autism. After one year as a Head Start teacher, I returned to school to embark on a career as a special education teacher. To answer your question, it was David who determined my career.

As I completed my special education coursework, a new program for children with autism was starting in Jenison Public Schools, my home school district. If I did not have the pages of my journal next to me, I would simply share with you that I interviewed for, and was offered, the position. That's true. What's also true, though, is that I was young with a few important pieces missing. According to my journal, the special education director and another woman, Bernice, conducted the interview. I don't remember Bernice, but my journal does:

*To my right is an older woman who I decide I would never want to work with and she is (oops!) introduced as Bernice, a potential principal. Feeling as conspicuous as a white bunny in dark woods, I cautiously find myself saying that I would most like to teach in the autistic program if I had a choice between a resource room or the autistic program. A sigh of relief from Bernice as if perhaps I have aided some sort of decision. I find myself focusing on an owl on the wall and just as quickly giving myself a psychological pinch to PAY ATTENTION. The questions – there seem to be thousands of questions – I answer – some well, some with a tremble in my voice, and one “I’m not familiar with that...” that leaves me in a full choke.*

*I’m saying words, but what am I saying? I give myself warning that I am speaking TOO GENERAL. I remember the notes I wrote to answer this very question – one by one the details come back to me. I relax. In three minutes I almost feel that I am that very special teacher, that the job SHOULD be mine. How can I feel so at home with a job I know so little about...with the thoughts and distorted impressions of children I have heard about, but never met? I want this job. Please, I want THIS job.*

There were two years of classes and student teaching between leaving Head Start and the call offering me a teaching position in the classroom for children with autism at Jenison Public Schools. I was so happy! Sensitive beyond all reason, I was crying before the call ended. I could hardly talk. I didn't realize that my tears over the next few years would be extraordinarily frequent. There were A LOT of things I didn't realize. It was a little bit like marriage, I guess. A bit of ignorance is a good thing.

I set up my classroom. I didn't know what materials to order. And what do I place on the walls? I selected a phrase from the 1965 song by Simon & Garfunkel, *Sounds of Silence* to display along the top of the classroom wall in large letters cut out of Contac® paper: *Hear my words that I might teach you. Take my arms that I might reach you.* On the opposite wall: *God, grant me patience and DO IT NOW.* I was ready.

Question #2: Would you say dealing with those who have autism takes a toll on your life personally?

When I read this question for the first time, I smiled and immediately thought, "No... just the opposite." I didn't know how I'd expand on that answer though. Equipped now with my journal, I have details that I can share with you.

I began the fall of 1976 with the traditional teacher expectation of affection and adoration from my students. At Head Start I thrived on the feedback of my preschoolers. David was the only child who was largely unresponsive, who didn't provide much feedback or affection. Now, all of my students had autism. I hate to admit it, but I had a severe need for applause from somewhere, anywhere. Maybe it was due to teaching-in-isolation. There were no other teachers of children with autism to talk to or to share ideas with. And for me it would have been threatening to actively seek them out. I was afraid that others might see my uncertainty about what to teach, and how to teach it. I desperately wanted a colleague as long as he or she would approve of what I was doing even though I didn't know myself.

Without a colleague and small but infrequent feedback from my students, I turned to the parents of my students for affirmation. The evening of the annual school open house took on an emotionally exponential importance for me. I tried everything possible to convince at least one parent to attend. I sent a 'hold the date' note home weeks in advance, and several written reminders as the date approached. I called each parent personally the week of the open house. As one of them noted, "Carol, this open house is really important to you, isn't it?" To no avail, one by one they shared that they could not attend. From my journal in 1976:

*Open house. Why is it that the most normal of school functions find me in a rather abnormal state? I might have been okay if I hadn't seen Ann in the hall as I arrived. She talked about the crowd of parents that would be visiting her classroom. Then she asked, "Are any of your parents coming?" That did it. I held it together until I passed my classroom's threshold.*

*I tried to gain control of pressing tears without success. UGH! Crying AGAIN. Where do I hide? My classroom has a bathroom designed for young children. It is very small with barely enough room to stand. Looking at the miniature toilet and sink I felt awkward. This is stupid. The thought crosses my mind that supposedly I am a big girl now, but this child's bathroom serves as an insulting match for my behavior. The tiled walls and floor seem unusually cold. I wish I could stop crying. I use the toilet paper to dry my eyes only to have the tears return. Defenseless from my own tears and with my back pressed flat against the wall, I sink to the floor. Tonight was my first open house and I spent it on a bathroom floor.*



About this photo:

This photo was taken in the fall of 1976. We are on the school playground. It was easiest for us to go outside when everyone else was indoors. My first four students, from left to right: Michael, Kimberly, Elizabeth, and Mary.

Reading my October 26, 1978 journal entry – now two years into my teaching career with eight students – affirmation was still an enduring, 'die-hard' expectation of mine:

*Not a good day. Michael took every conceivable container methodically to the edge of the sink, hopeful for the opportunity to fill it with water, turning with a guilty "Hi..." when spotted. Angie had a case of the autistic giggles. Kimberly...Kimberly knew just where not to be, and just what not to do, and she was there, doing it, all day. Eric was okay, save the usual combination of extreme stubbornness and co-operation that is Eric. Tanner threw things about the room. He emptied trays of sorted papers that resulted in the loss of a sheet of data on Jenny. And Jenny, she was constantly in my desk drawers, selecting paper clips and an old drawer knob to focus on. Mary seemed unaware of the frenzied tempo of the day. Kate was exceptionally good, except during rest time at the end of the day. She simply could not stop verbalizing or moving.*

*And me. I felt the usual series of frustrations that accompany any day like this one. I started it near tears over the fact that Mary's mom has yet to respond to my repeated joyous notes home that Mary can now add. This is no job for applause. A clap now and then would be nice. I missed it, no needed it, today. I felt empty, too. Stepping aside to laugh (so I wouldn't cry) amidst the compulsions and seemingly endless frustrations of the morning, I was struck with a sharp realization... I want the behavior plans to be effective, consistent, the best. I want the academics to be relevant and appropriate. I should say, "My reward is seeing them learn." But it's not. When they learn, I feel that I'm doing okay. That certainly I presented the lesson correctly, asked things in the right way. But that is not rewarding. It is just a relief to me.*

*Autism isolates my students, their parents, and me... but what makes it so difficult is that it feels like I am the only one who is lonely. I am working so hard because I want someone to acknowledge that I am here.*

I began my career with a fragile understanding of applause. Applause is not why any of us are here, it is not why we came, and it is not a reason to teach. I would not have learned that in any other classroom, at any other point in time.

I have learned so many other things from individuals with autism and their families. What they have taught me I can't imagine living life without. Jigsaw puzzle pieces are often used to represent the unanswered questions of autism. Flip that around. I believe that if I had *not* spent much of my life working and learning alongside people with autism I might now feel that I still have the "...few important pieces missing" that I referred to in my first answer. Teaching people with autism has kept both of my feet squarely on the ground, held my attention and focus, and filled in the vacant spaces within me... occasionally via tears and an open house or two on a bathroom floor.

Question #3: What is the biggest challenge you face in your career (or biggest challenge associated with autism)?

The confusion.

Question #4: What would you say has been the most rewarding part about your job?

The confusion.

Confusion has played a central role in the field of autism. It has been and continues to be the greatest threat to my work - and also the most valuable and largely untapped gift - at the same time.

When I first began my career the average 'life span' for a teacher of students with autism was less than six months. We weren't lasting very long. It was a revolving door turnover of teachers, a phenomenon that threatened to continually provide children with autism and their families with inexperienced teachers. In my journal I must have written '...this is my last year...' twenty times. Confusion is an uncomfortable feeling. Basically, people like to know what they are doing. The threat is that confusion makes people vulnerable to snake oil salesmen, incredible claims of success framed by charismatic appeals. From an article I wrote in 1997:

*Confusion is uncomfortable for us. People like to know what to do. Knowing what to do is reassuring, and makes us feel secure, competent, intelligent, and in control. This can result in a "McFix" approach – a desire for quick answers, conclusions, or solutions. This also makes us vulnerable to believing any solution that is presented to us – even a really bad one. It doesn't have to be a solution in this case; it just has to be presented with that implication.*

*Atypical behavior is confusing. It makes us uncomfortable. This places us at risk for fast and ineffective solutions. Adding to the confusion are other people who share their convictions (assumptions that have gone*

*absolute) regarding the reason a specific behavior is occurring, without taking the opportunity to be confused. It is common for us to believe that doing is equal to knowing what to do. This is not always true.*

I believe that during the 1970s the teachers who stood the test of time were creative types who – when pressed hard enough – learned to be comfortable with confusion. Little by little and never all at once they learned that curiosity is confusion with a good attitude. This allowed them to relax and notice things that others missed. Confusion can lead to discovery, but you've got to be calm enough to think. You have to be comfortable with confusion to discover its value.

Quiet moments were important, because it was there that I began to notice that my students perceived things differently than I did. Still, the ongoing battle between uncertainty and discovery would replay over and over again for several years. Many of my journal entries describe this struggle between the threat - and largely untapped value - of confusion, often within the same paragraph:

*Sometimes I look around my classroom and I don't know what I am seeing. I can describe only how it looks. I am so used to understanding what I see. That isn't possible here. More puzzling is to wonder what each of the children is seeing. Perhaps seeing the same thing, but each and every one of them perceiving it differently? I become disheartened when I talk myself into believing that I will never know the world that the children know, and that they will never know mine. It's a destructive way for a teacher to think, so I never let myself dwell on that for too long. Not for too long...but it crosses my mind often.*

When in the middle of an overwhelmingly confusing situation, you don't understand what just happened, what's happening, or what will happen next. It's a little like being a buoy on an ocean, except that the less you can predict your experience, the more you get tossed, vulnerable to being taken 'off guard'. Remember the first open house on the bathroom floor of my classroom? It ended this way:

*I made my way out of the bathroom. I talked with one set of parents all night, to help them find their son's second grade classroom. In a very uncomfortable way I wanted them to stay. But, they are not 'my' parents. Alone again.*

*In the final minutes of the open house, I set a mousetrap under the sink as I prepared to leave. A voice behind me changed my plans.*

*"I would have come earlier, but..." Mrs. DeWitt, Kimberly's mom, is suddenly behind me. I closed the doors below the sink with the trap inside and turned. My enthusiasm is tired. I wish my eyes looked better.*

*Mrs. DeWitt and I sit at a table in the middle of the room and talk for forty-five minutes. I show her some of Kimberly's activities. She doesn't say very much until she asks, "Will Kimberly ever talk?"*

*"If I have anything to say about it, she will." Confident words spoken with a voice that is very tired.*

*Because of Mrs. DeWitt's late visit, I am the last teacher to leave the building that night.*

Kimberly never did talk. However, that is not to say that she didn't learn to communicate and connect with us in her own way. With Kimberly, we had to watch very closely so as not miss the giant steps:

*I remember the first time Kimberly took Elizabeth's hand. Elizabeth had reached for Kim's hand first; then the grasp was broken. Slowly, with an apprehensive trust, Kim's hand pursued Elizabeth's. Kim did not look at Elizabeth. As always, Kim's gaze was opposite where it needed to be; her hand moved as if it had a sense of it's own until it closed around Elizabeth's hand. If the world breathes, for that moment I am positive it stopped. It had too. Because Kim - or maybe just her hand - had sought out another hand and closed around it. I wonder why I didn't cry at THAT. I guess as a rule teachers don't cry when a child finally grasps what they have been teaching. It's just a part of the day. Kim reaches for our hands quite frequently and easily now.*

I was perfectly placed in time to begin my career when I did. It was a hand-in-glove match of my strengths, my position, and autism's dark ages. I would not realize that for several years. Looking back on it, I thrived on the confusion enough to override the discomfort of it. Working alongside people with autism, their families, and the many professionals working on their behalf has been an honor and a privilege for me. I consider myself very, very lucky.

Question #5: What advice would you offer to someone interested in this career?

This is my advice to anyone interested in working on behalf of individuals with autism:

- Read about autism, learn about the experience of individuals with autism and their families, and explore it thoroughly *before* beginning to picture yourself as a part of this incredible field.
- There are so many career options, take your time in deciding exactly what role you want to play.
- Consider what each university has to offer in terms of training, not only in terms of autism but also in terms of your specific career choice.
- As you compare universities, look also at who will be your teachers. Are there experts on staff who have practical in-the-field experience?
- Starting now and throughout your college career, seek out experiences in line with your goals to complement your study with first-hand on-the-front-lines opportunities.
- Embrace confusion, ask questions, and always be open to discovery.

Wishing you all the very best as you complete your Senior Project and embark on your career,

Carol Gray