

Being Open to Surprise: Fostering New Possibilities in Our Interactions with Deafblind Persons by Examining Assumptions about Voice and Power

Barbara Miles

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A number of years ago when I was a relatively new teacher of children in the Deafblind Program at Perkins School for the Blind, I had the occasion to write a paper based on my teaching experience. That was the first "paper" I ever wrote in this field. I read the paper to some staff members at Perkins as part of a conference being convened by Mississippi State University to hear from some teachers that had been identified as "exemplary." Apparently someone at the time had recommended me as a pretty good teacher. It was probably Mike Collins, who was my supervisor at the time. Or maybe it was Chris Castro, the supervisor of the older children. Anyway, it was Mike who sent the paper I had written to the journal that was then called "Deaf-Blind Education" (now the DbI Review), and it was published there. I have no doubt that I would not have had the career I have had without Mike's confidence in me, both as a writer and as a teacher, and I wish to remember him with deep gratitude today.

And, equally, I must acknowledge my debt to the confidence and friendship that Marianne Riggio has shown me over these many years. She has supported my work over decades. I am sure many of you at this conference would say the same thing about her -- her dedication has been an inspiration to hundreds of teachers and leaders in this field. At some point Marianne even had the wild idea to invite me to write a book with her, which -- after 6 years of work, and countless hours of discussing each and every sentence -- became Remarkable Conversations.)

I mention these people now because they taught me about what effect collaboration, confidence, curiosity, trust, respect, listening, and genuine conversations can have. These are guiding principles that, in my view, need to govern all our interactions, including those with people who happen to have deafblindness.

And it is because of this legacy that I want to return to the original idea of the original paper that Mike Collins sent to Deaf-Blind Education. That paper included some of what was then current research in the field. But it was based primarily on two things. One was a book I had read outside the field of Deafblindness by a psychologist named Adolf Guggenbuhl-Craig. The book was called Power in the Helping Professions. That book

had a profound effect on me, and has colored my relationship with my students over all these years. What he said was basically this: if there is not a genuine relationship between two human beings based on a sense of equality and respect, then a power relationship is likely to evolve as the only way of connecting the two people -- whether these are social-worker/client, teacher/student, clergy person/parishioner, doctor/patient, or supervisor/employee. Equality, respect and genuineness are the operative words here.

The second thing I included in this original paper was a couple of stories about one individual student. I am convinced, even today, many years later, that I have learned fully as much from him as he had (I am sure) learned from me.

I later went on to make this mutuality, these genuine conversations, and this striving toward an equality of respect for each other, as the central guiding compass of my career. And, I must say that it has made for a career full of joy and continual learning. (Not without its challenges, to be sure.) I now frame what I have learned from the many Deafblind people I have met over the years as a teaching in how to stay present and mindful -- in short, how to stay open to surprise in each and every interaction.

So, here are some stories of particular people with deafblindness, and their parents and their teachers, all of whom have been my teachers over all these years. These are by no means the only ones I have learned from. I would like to be able to say that I have learned from every student and teacher and parent I have encountered, but I am sure I have not been quite that exemplary. I have aspired to this, however, and continue to feel it is worth aspiring to even as I now look at retirement.

One of the first young persons with deafblindness that I met, many years ago now, was a 7-year-old whom I will call Luke. What I remember about him is condensed into a particular moment. The day I first encountered him was in a playroom full of perhaps 15 children, most of whom seemed completely engaged (or lost) in their own isolated worlds. Some were running around, some sat and rocked or lay down, some flapped their hands in front of their faces, or stared out the window, or spun around in place. I remember a moment when somehow Luke ended up on my lap on the floor -- I might have appeared to him to be like a chair, I don't know. Anyway, he was sitting on my lap, leaning back against me as I sat cross-legged, and his little hands were face up in his lap. I glanced down and saw his palms. I immediately noticed that they were not at all like most young children's palms I had ever seen. They were each an intricate criss-cross of many many lines. They seemed to me like the palms of a very, very old person. And I clearly remember having the thought, "These are the hands of an old soul."

Now, I know that the word "soul" is not a word that is used much, if at all, these days, in educational literature. I am not even sure I could define what it means, but I do know it has a resonance for me. (Thanks, Dr. vanDijk, for inserting that word forever into my

world!) The word "soul" points to a kind of mystery, an unknown quality in each person that cannot be measured or captured, only respected.

That moment with Luke has never left me, and seems somehow to have launched me on a journey of seeking to learn from each of the Deafblind persons that I have met over the years, which now must number in the hundreds. Since that fortuitous moment with Luke, I feel drawn to approach each child or adult as unique. This person in front of me is a soul, a unique being with his or her own history and spark of life. No matter what abilities or disabilities, this is a person worth knowing as an individual, a person worth being interested in, a person about whom I should never make any final judgments. None. I need to always be open to surprise. Easier said than done, of course.

I don't know what happened to Luke after the short time that I knew him, but I hope that, if he is still alive, he has at least one or two people in his life that recognize his old soul, at least some of the time.

Sometimes (often, in fact) it is challenging for me to remember the unique soul-quality of each individual, especially when I am put in the position of people looking to me as an "expert" of any kind, or myself feeling the pressure of needing to be an expert, needing to "know" what to do to "help." Not that my experience of learning about the effects of living with limited vision and hearing counts for nothing -- it helps a great deal, in fact. The field of educating Deafblind children has progressed immensely since I joined it over 40 years ago. But/and -- first and foremost, it is always the soul, the personhood, the unique experience of this particular unique being that I hope will be my guide. And, I must add, the mystery of the uniqueness of each one of us.

Gradually, over the years, this coming to know so many individual persons with deafblindness has translated into my life as a whole in its own way: I realize more and more that I can't, ever, put *anyone* into a box. I must always, always maintain a "beginner's mind" (as a Zen master once said).

Another way of saying this is that I must always be *open to surprise*. Life, after all, is ultimately uncertain. So we must leave space for uncertainty in all our interactions. We must remain present for each moment.

So, now, some more stories of what has occurred when I have allowed myself to be in this alert, relaxed, light-hearted state of openness:

In my very first year of teaching I had a student whom I will call Frank. Frank was a spirited 8-year-old child whose deafblindness was the result of the Rubella epidemic of the 1960's. He was severely deaf and had quite limited, though usable, vision.

Nearly every day when Frank came into the classroom, he wanted to talk with me about roller coasters. He would wriggle with delight and make the sign, like a roller coaster

going up and down, and attempt to say the words. He just *loved* roller coasters, and had grown up going to ride on one near his home in the summers. His interest I quickly labeled in my mind as an "obsession," since it was all he seemed to want to talk about most of the time, and since I was a beginning teacher with what I considered to be very important things to teach him. He would make the sign for "roller coaster" over and over many times during the day and try to engage me in his interest. Though I was tolerant of him, I tired of this topic quickly, and tried constantly to shift his attention to what I considered to be the more important lessons that I had prepared for him, with more or less success.

A number of years later, after Frank had graduated (and I had lost touch with him), when he was about 30 years old, I think, someone told me that he had a website. He had been fascinated by computers since they had appeared at Perkins in the 80's, so it didn't surprise me. Anyway, I looked up his website. And what do you think I found when I went there? You guessed it -- *roller coasters*. He was a member, as an adult, of what I remember now was called The American Society for the Preservation of Historic Roller Coasters. His website had pictures of himself standing in front of a number of this country's most famous old roller coasters. He had worked to save money, traveled to those places, taken pictures, acquired the skills to make a website -- all for the love of roller coasters. Something I had labeled as an obsession.

This was a moment of realization that crystallized quite a lot for me. While I had, over the years, grown in my ability to actually be interested in the things that my students were interested in, I had not, I don't think, fully realized the extent to which these interests were serious things for them, sometimes serious things for a whole lifetime. When I saw Frank's website, I saw that these interests were the avenue for his motivation and learning that eventually drew him to develop himself toward his own particular place in the world. I saw that genuine interest is intimately related to capacity. Frank developed his capacities around his interest. His capacities were fueled by his interest.

And, don't we all have these? Things that draw our attention, things that we love so much that we are called to do our best in service of them. Think about it. For example, an interest in deafblindness is a relatively rare interest in this world of billions of people. And, yet, I (and may be true for many of you who are reading this) cannot begin to explain the depth of connection and the journey that this interest of mine has taken me on over these many years.

And, each of you has your own experiences, your own particular soul-reasons for this interest and for the other interests that you have. If you are either a person with deafblindness, or if you are a parent of a child with deafblindness, you likely did not choose this interest -- it chose you somehow. And, perhaps your journey is one of living with the riddle of how you came to be Deafblind yourself or the riddle of how you came

to be the parent of such a child, what meaning this has for you. Each one of you will need to live your own way into your own answer, and each answer will be unique.

Those of us who have chosen this interest as a career must have our own inner reasons (I say "inner" in large part because I seriously doubt if very many of us have made this choice in order to get rich!). We must be doing it because of something else that draws us. For myself, I can only say that it has been, and continues to be, an interest and love that has drawn forth the best in me, and for this I am grateful beyond words.

Another story occurs to me that exemplifies how a small interest can open up a whole world for a Deafblind person, and for ourselves as teachers or interveners or professionals as well. And, it might even be, given this, that our own interest in deafblindness can, for each of us, open up worlds, if we allow it to.

A girl whom I will call Cindy was a totally deafblind girl who came to Perkins for an evaluation when I was on the evaluation team in the 1980's. She was 7 years old when she came, and had been at home with her family for her entire life. She was well-loved, which was obvious from her endearing personality and her contented comfort with herself and other people. She was nearly entirely without language, though, as her parents didn't know any formal sign language, and her total deafblindness did not allow any other possible avenues for accessing language other than tactile sign. Her family did, however, in addition to giving her exceptional care and love, develop a few home signs together with Cindy.

When I was getting to know Cindy during the evaluation days, I was curious to discover, among other things, her potential for learning Braille. I asked her mother what her favorite things were. Her mother told me that she loved to play with window shades -- the kind made of a sort of canvas that you pull down from a roller at the top of the window. She said Cindy would stand for long stretches of time and pull down the shade and then let it go up. Down and up, down and up. And she would finger the material, apparently liking the particular texture of it. She loved doing this so much that she and her family had developed a simple home sign to talk with her about it -- it was the natural gesture that Cindy already knew in her body, the gesture of pulling down the shade and feeling it go up again. Cindy had learned to use that gesture to ask to be taken to the window where the shade was.

[If you find yourself interested in how languages develop from the ground up, as in the development of home signs -- you can research the relatively new and organic development of a sign language in Nicaragua by entering the phrase "linguists study development of new sign language in Deaf Nicaraguan children" into a search engine.]

It occurred to me that maybe I could use Cindy's interest in shades to assess her aptitude for learning to read and write Braille. So I tried to think of where there was a shade for us to play with in the Hilton Building (then the North Building) at Perkins

school. No luck -- all the windows had blinds of one sort or another. Or curtains. Then someone on the evaluation team had the suggestion that the big movie screen in the auditorium might be very like a shade -- it came down from above, and was made of a similarly textured material. "Good idea," I thought. So we tried this, Cindy and I. First I got out a Braille writer and invited her to feel as I brailled the word "shade" on a little index card. Then I used her home sign and invited her very carefully to feel my hands as they made the sign. (By that time I had become pretty strict with myself about always leaving a child the freedom of her/his own hands, and it hadn't taken Cindy long to catch on to this invitation.) Her hands followed mine as I signed, and as I put the card in my pocket so she could feel it there as we walked upstairs to the auditorium, me stopping and signing "shade" over and over again as we went. If my memory serves me right, she seemed to begin to anticipate -- she was smiling and her body was making excited movements.

When we got to the auditorium, I invited her to come with me as we went to the podium with the controls that operated the screen, and to feel as I pushed the button. When the screen came down behind us -- a **huge** screen, I might add -- I invited her to feel the screen as it lowered, and to explore it all she wanted. She was ecstatic as soon as she felt the fabric of the screen, which was similar to the shades at home. The biggest shade she had ever seen! The king of all shades! A miracle! Her own little body shook with excitement. It was then that I gave her the index card with the Braille word on it: "shade." Those little dots -- they stand for this thing that you love so much! That's what I was trying to tell her. The first time I showed it to her, she was mildly interested, but during the several evaluation days that I shared with her, and during the repetitions of this routine of brailing the word "shade" and then going to explore the giant shade together, she came to treasure that little index card. She held it close to her for days after that initial experience. It somehow had a kind of magic for her. I suppose that in some ways this experience was for her a bit like the Helen Keller "water" moment at the well, though it concerned Braille rather than fingerspelling. I had always doubted that Helen Keller story, but no longer doubted it after the experience with Cindy.

I suppose if I were to condense that moment into a wisdom that people who live with deafblindness can teach us, it might go like this: Language is a miracle. Signed language. Written language. Spoken language. Fingerspelled language. Brailled language. A miracle. Having been with a number of children, or near to them, and their teachers, as the miracle of language began to dawn on them, I can attest to the miraculousness of it. Imagine. I can write these words, or speak these words, or sign these words, and you can read them in one way or another, or hear them, and images form in your mind. There is a connection between us, a transfer of something, a communication. I never cease to be amazed by this.

The word "shade" was the beginning of literacy and sign-language learning for Cindy. It opened the door to these forms of connecting with the world. It was the beginning of

her wanting to learn Braille, because it was so closely associated with what **she** loved. It was close to her body, close to her family, it had real meaning for her.

Cindy did, in fact, learn quite a lot of sign language and Braille during her time at Perkins, especially given the fact that she hadn't learned any formal language before the age of seven. And that fortunate discovery of her love of shades, and that particular word, was the "key word" that opened the door to sign language and literacy for her.

One thing this highlights for me is that not just any words will do to unlock language-learning for a Deafblind child. The first words we offer to a child must emerge from them, must be *their* words. Shade. Roller coaster. What might have been your own first spoken word? Written word? Do you remember? It occurs to me that it is not for nothing that we use the expression "mother tongue" to describe our first language. Some words are close to us. They might even be said to be soul words in some way.

[If you are interested in learning more about this notion of "key vocabulary," which has guided me since my early teaching days, I refer you to a book called Teacher by Sylvia Ashton-Warner.]

Knowing Cindy, participating in this experience with her, has deepened my own interest in, and love of, and respect for, words and language and the origins of language. My own interest in the roots of words, in where language comes from, has been strengthened by seeing the power that a single word can have for a Deafblind child. Being mindful (and I use that word "mindfully") of the power of words has motivated me to be more careful with my own words, to be aware of choosing words with as much awareness as possible of the resonances that each word has. Full disclosure: I was an English teacher in a junior college before I stumbled upon the profession of teaching Deafblind children and somehow trusted that it was a calling for me. And, without my directly intending it, my respect for words and language and the origins of language has deepened immeasurably as a result of my knowing Deafblind children. These children make the teaching and learning of language into a very down-to-earth, close-to-the-bone experience.

In addition, my experience with Cindy, and many other Deafblind people, has had the effect of deepening my interest in the tactile, kinesthetic and material world. It has sharpened my own perception of the world around me. Both Frank's and Cindy's key words were words that had associations with bodily experiences, not with abstractions or ideas. We live in a culture (especially in the United States, at any rate) that tends to view material things as mere conveniences, not necessarily as companions or things of value in themselves, things that can be felt, touched, lived *with*, not at a distance from.

Many of you may have heard or read the quote from Jacques Lusseyran, the Frenchman who became blind a child and wrote of his experience of learning to see the world with his hands, in an entirely new way. Let me quote what he says:

As soon as my hands came to life they put me in a world where everything was an exchange of pressures. These pressures gathered together in shapes, and each one of the shapes had meaning. As a child I spent hours leaning against objects and letting them lean against me. Any blind person can tell you that this gesture, this exchange, gives him a satisfaction too deep for words.

Touching the tomatoes in the garden, and really touching them, , touching the walls of the house, the materials of the curtains or a clod of earth is surely seeing them as fully as eyes can see. But it is more than seeing them, it is tuning in on them and allowing the current they hold to connect with one's own, like electricity. To put it differently, this means an end of living in front of things and a beginning of living with them. Never mind if the word sounds shocking, for this is love.

You cannot keep your hands from loving what they have really felt.

[Lusseyran, J. (1987). *And There was Light*. New York, NY: Parabola Books.]

What Jacques Lusseyran learned was to inhabit his body, to see with his whole being rather than just with his eyes. He learned to truly belong to the physical world. Cindy didn't have any language to speak of such things, but I imagine her experience was similar in a way, and also something she knew from birth, since she never knew anything other than total deafblindness. She never had lived at a distance from things, but lived intimately with each thing she could touch, that touched her. As well as with each person she touched or who touched her. And the two were inseparable in her personality, which was full of warmth for both people and things.

Cindy ended up enrolling in the Deafblind Program at Perkins soon after that evaluation experience. I didn't ever teach her directly, but I encountered her regularly in the hallways, and she (happily for me) forever associated me with the "shade" experience, and always seemed as delighted as she was during that first encounter with the enormous shade. I sometimes thought that she imagined me to be "the queen of shades" -- having produced such a gigantic one for her delight, such a tangible manifestation of her greatest interest. I was always touched -- and often surprised, I must say -- by her delight in "seeing" me that way. Even now the memory of her and those encounters in the hallways of Perkins brings a smile to my face.

It is no accident, I think, that we say, "I was touched by that experience," when what we mean is that we were deeply affected. (I happen to have learned recently that the word "touch" has the longest entry in the Oxford English Dictionary.) So many people with deafblindness seem to be more deeply touched by things around them than ordinary folks are. (Not that anyone is "ordinary" -- only that most people are not deafblind.)

Vision and hearing tend to put us at a distance from things. May we remember to allow ourselves to be touched. By this I do not mean to let ourselves be bowled over with pity or excess emotion, but merely able to contact each other in genuine ways, and contact the world in genuine ways.

Another thing about Cindy struck me during those few days that I knew her, as her evaluator. It is a quality that strikes me about many children and adults with deafblindness. That is a sense of trust that she had in me. I attributed Cindy's trust in me to two things. First, it seemed to be result of the trust she and her parents had developed with each other from the beginning. Like I said before, I could sense this in the comfort and warmth that Cindy exuded in her personality.

Second, Cindy's trust in me seemed also to hinge on the presence of her mother during the several days of evaluation time. Her mother not only provided information crucial to the evaluation process, but also acted as a quite literal physical bridge between Cindy and me. Cindy was allowed, and invited, to touch me and her mother at the same time, so that Cindy had a bodily knowing of her mother's permission to trust me. As if she understood in a tactile way, "Any friend of my mom's is a friend of mine" (even without any language to express that). In reflecting on this now, I feel touched and grateful for the motherly intuition that guided Cindy's mom to act as she did, both in the years that led up to the evaluation time, and also during the evaluation.

Of course many young children, both those with deafblindness and those without deafblindness, don't easily give trust to a stranger. So much depends upon the earliest experiences of each child and each family. May I insert here a bit of advocacy for early identification and early parental support programs that encourage the development of such trust. They can truly make a huge difference in the lives of children throughout their lives, and especially in the lives of children who are born into families who are very likely overwhelmed by an early diagnosis of deafblindness.

One more thing that struck me during that time with Cindy is that being a person with deafblindness requires a great deal of courage. What must it be like to be in a position of needing to depend on countless others for their connection with the world in order to survive, as a person who can't see and hear must do? I have reflected on this quite a lot in my life as a result of my contact with Deafblind people.

Actually, when you think about it, we all must depend on others to survive, all day, every day. But, the illusion that we are each "independent" (and I do believe it to be an illusion) can become unconscious as we grow older. Without being much aware of it, we can come to fancy ourselves to be independent, especially in a relatively rich culture where we are comfortable and can usually buy for ourselves the things we need to eat, clothe and house ourselves. Not Cindy, and not most children with deafblindness. They must depend on the kindness of strangers. We who can see and hear must, too, actually, but we just don't remember that very often.

Which brings me to talk about how they call forth the best in us. I remember hearing Norman Brown, the father of a young man with deafblindness, speak of this. I can't remember his exact words, but what he pointed to was this fact, which many reading this might have experienced: It is possible to walk past a person who is Deafblind, and they most likely will never know you were there. They can't see or hear you, after all. You can ignore them without being subject to their gaze. But once you realize their personhood, your best self is called forth by their simple presence, and by their need to trust and depend on the world around them. When you approach and seek to make friends and connect with them, or even simply sit beside them for a while in a gesture of companionship, you do so not because of any accusation they will make, nor for any acclaim. You do it out of what is most human in yourself.

Respect is the operative word here. Respect of both the deafblind person and yourself. Respect meaning the willingness to not make any assumptions, to look afresh at this person (including ourselves!), the willingness to make a genuine connection, the willingness to be open to surprise. I have always loved remembering the root of the word "respect": it comes from the root "spec," (same root as in the word "spectacles") with the prefix "re-" (meaning "again"). So "respect" literally means "to look again." To really respect someone is to always, always to be willing to look again at them, not to put them in *any* kind of mental box. Back to where we started: true respect means being willing to be open to surprise. This goes not only for Deafblind persons, but for every person, as far as I am concerned. A tall order, to be sure. One that I, personally, fail at over and over. But what is one to do? Nothing to do, except to forgive oneself, respect oneself, and to keep moving toward this as a worthy goal

Now I want to tell you a story about a person whom I will call Paul. (This story, or a version of it, was included in that original paper that Mike Collins submitted to Deaf-Blind Education in 1990.)

This story is about things that happened when Paul was about 17. At that age (understandably, given his adolescence) he developed an interest in going into the army. I was his teacher then, and I felt it was my responsibility not only to empower him, but also to teach him the "ways of the world." So I told him many times, as gently as I could, how I thought that it was impossible for him to join the army, deaf and totally blind as he was. He would have none of my realism. He got it into his head that *I* was the one keeping him from joining the army and fighting for his country. We butted heads for months.

Until my supervisor, Chris Castro, suggested that Paul should just go ahead and apply to the army. He needed to find out for himself, not just depend on my say-so. So I helped him do that. He wrote a letter in Braille to the local army recruiter, and I wrote the print translation on it, and we walked to the post office and mailed it. Three weeks later he got a polite and kind letter from a sergeant, which I put into Braille for Paul.

The sergeant thanked Paul for his interest, and said that it would be too dangerous for someone who was deaf and blind to be on the battlefield. Paul was disappointed, but believing: an army sergeant had spoken. For a couple of weeks I thought that was the end of it.

But then he wanted to join the air force and be a pilot. He was certain he could do that. This time, a bit wiser, I just suggested he write to the air force and see what they said. Some weeks later he got another polite letter back, thanking him very much for his interest, politely telling him that his blindness and deafness disqualified him from service in the air force. Then it was the navy, the marines, even the coast guard. The process of composing letters and receiving replies lasted the better part of a school year.

After the armed services were exhausted as career opportunities, Paul decided he wanted to go to medical school and become a doctor. So he wrote to med schools to find out requirements. Four years of biology, three of chemistry, two of physics. We had long discussions about what these courses might be like, what he would be required to do and learn. After months of thinking about it, he decided it would be too much for him, given his challenges.

Paul graduated several years later with a high school diploma. After some searching, he landed a job with a company that manufactured heart-lung machines. His hand skills as a blind person were so good that he was able to assemble tiny parts with amazing accuracy, and he had excellent concentration and work skills. Until the company went under a number years ago now, he was earning more money than I was as a consultant.

While he still was working for that company he came to visit me one summer in Vermont. One evening we were sitting on the couch in my little house, reminiscing about friends we had in common. One was a fellow teacher, whose husband was a doctor at the time. Paul said to me, in sign language, "How is John?" "He's fine," I said. Paul read my sign language with his hands, feeling my hands as I signed. He paused for a moment. Then he asked, "Is he still a doctor?" "Yes," I signed. "He's still working in the emergency room." This time Paul kept his hand on mine as he thought, waiting for his next words to come. After a bit, he signed, "I couldn't be a doctor ... it would be too hard for me I am Deafblind." Then he took his hand away and drew back into himself. I left my hand on the couch between us. His face was expressionless for a long time. After what seemed like many minutes, I saw him smile. Then his hand reached over and found mine on the couch. When he was sure I was paying attention, he signed, carefully and proudly, "I bet John uses the machines I help make in his emergency room."

There has been so much learning for me in this whole process, in this journey over the years with Paul. He still visits me every so often during the summer, and each visit brings its own learning.

There was first of all the wisdom of trusting Paul to interact the world himself, to discover things for himself. To learn by doing that. To learn to trust himself and to trust the wider world. I had to give up a certain amount of control in order for Paul to really learn what he needed to learn as an adolescent. From this distance I can see that the fact that I didn't even think of letting Paul try to join the army most likely came from a perfectly fine and normal desire for me as a young teacher to protect him from what I knew would be inevitable disappointment. I needed the support and guidance of my wiser supervisor to have my back then -- to allow him to take the risk of going after what he wanted. She knew that he deserved to try to do what he wanted to do, however impossible that seemed to me at the time.

From this distance I can see that my desire to protect Paul contained a certain amount of pity and a dose of what I might now call condescension. Neither of those was faithful to his personhood, to the best in him, to his genuine capacities. Just because he couldn't join the army, or be a doctor, didn't make him one whit less of a human being than the most powerful or "successful" person on earth. He didn't need any pity from me or anyone else. He just needed access to an opportunity to interact with the world on his own terms, and people around him who saw his capacities rather than his incapacities. Isn't this what we all need? People who believe in us enough to give us opportunities, and guidance and access enough to help us find our own unique capacities and places and communities in which to express those capacities.

And then, years after all that letter-writing and finding out for himself, there was that one moment when Paul, then a 30-something, sat on the couch with me and reflected on his own growth from adolescence. I might easily have missed it if we had not shared that silence. If I hadn't let Paul ponder his life in his own way. If I hadn't learned, together with Paul, over the years of knowing him, to slow down and trust the silence, to trust the waiting. It takes *time* for many, if not most, Deafblind people to process things, more time than we are used to spending in our fast-paced world. Had I not waited what seemed like interminable moments, letting my hand rest near him so he knew of my presence, Paul might have missed the opportunity to reflect and realize for himself his own real value as part of society. In those moments of quiet, he realized the interconnectedness of us all: the machine in John's emergency room would literally not exist with Paul's skilled hands to put together those intricate parts. He *knew* that, in his bones.

This realization, of course, has resonances for us all. How easily I can come to berate myself and to feel like because I have not achieved some of my early dreams that my life is therefore less than others' lives, or even worthless. But, wait. Literally. Wait. Do I think Paul's life is worthless? No way. He is an amazing human being. And he has knowledge, deep inside himself, of his own worth and his own place in the wider world, regardless of what we who can see and hear might call his "disability." Or, maybe even, *because* of it. Who knows?

At any rate, there are many reasons for his realization of his own belonging in the wider world, not the least of which is the secure relationship that he had over the years with his mother, who in spite of her own challenges, which were not inconsiderable, always had confidence in him. That realization on that particular day emerged into awareness for him when there was space for it to emerge, and when there was (thankfully!) my presence with him in genuine conversation, and my trust of the silence, the quiet.

That leads me to ask: Do I give myself that space in my own life? Space to allow myself to realize the small ways in which I do belong to the greater life of the whole? Because, after all, I do. We *all* do. It's a fact. We are dependent on each other for our food, our clothes, for the hospitals and the machines, for the cars we drive, for many small gestures that give us inspiration to get us through hard times. We are interconnected. We all belong, each one of us. We each contribute, in our own particular way. We each have our own unique capacities. And we each depend on others, in our own particular ways. Realizing this, at least for me, requires some regular slowing down.

I happen to have a private belief that Deafblind people are here to teach this world a lesson in slowing down, and consequently, about being open to surprise. (Among other things, to be sure....) This seems especially true for me as everything in the world seems to be becoming more fast-paced. When I think of Paul, and when he visits, I have the opportunity many times during the course of his visit to just slow down, to take an extra few breaths. And to trust the quiet, the silence. I am nearly always pleasantly surprised with what happens when I actually relax into the present moment, as I was in the moment when Paul and I were sitting on the couch. Trust. Slow down. Trust. Trust this moment. Be mindful in this moment. Just this. Just this moment. This has been an absolutely central learning in my life. And I have Paul, among many other Deafblind people, to thank for giving me this opportunity.

One more story about a Deafblind young woman named Patricia, who is no longer with us, but whose life affected many, many people. When I first saw Patricia at school, many years ago now, she was confined to a wheelchair, her brow was constantly furrowed, her fists clenched, her arms held close to her chest. Without words, but with the language of her body, she told of her displeasure at the school situation that was not suited to her spirit. Equally, when she was happy, as she increasingly came to be after her parents took on the immense responsibility of educating her at home, there was no mistaking Patricia's joy, sometimes quiet, sometimes more exuberant. Patricia let everyone know what evoked her joy: bouncing on a swinging bolster with her friend and occupational therapist; sailing and skiing (with wonderful adaptations); gardening in a place where a farm had built a raised bed to accommodate her needs; having many opportunities to help out and join in, in the ways she could, around her home; joining in delicious and carefully prepared meals. During all these times, and more, Patricia smiled, expressed pleasure with her voice, widened her eyes, laughed in her own quiet way.

I was not until her family insisted that everyone around her take her entirely seriously, and notice her bodily expressions as genuine communication, that she began to be a teacher for all of us around her. For one thing, in a way I shall never forget, she taught me, reinforced in me, the importance of absolute respect for everyone's hands. I only had the pleasure of visiting her once a month during this time. As I recall, it took several years of everyone around Patricia agreeing to *never* control her hands, even in the slightest, in order for her to trust that she had control over her own hands, which had been manipulated for so many years by others. Gradually, ever so gradually, she began to reach out and explore her world and ask for contact with people by putting her hand or hands on their hands as they interacted with her and with the world around her. Finally, she had direct contact with the world, contact which she herself could regulate. She could express her interests by reaching out and grasping and touching, which became a kind of language for her to express herself (along with her facial expressions, vocalizations, and whole-body expressions).

Another thing I recall with delight: an intervener of hers once said that Patricia demanded honesty, deep honesty. Patricia knew somehow when people were being false. When this intervener said this, some years after I had first gotten to know Patricia, I immediately knew what she meant. This quality of Patricia's -- that I learned not only from Patricia herself but also from her parents and from all the people around her who were trained by her parents and by each other -- was indescribably valuable for me as a professional (and as a person, I must say). During the meetings we had regularly for years at her family home, if I was tempted to slip into professional jargon, or into any of the many pitfalls that professionals (myself included) can fall into, Patricia would bring me back down to earth, back to the moment, back to what really matters. She would make a sound, or smile, or fall asleep in boredom from being ignored, or furrow her brow as if to ask a question. Or show us a texture or object she noticed by exploring it herself, or look with interest at a bright object across the room, or call attention to her presence and feeling of belonging or wanting to belong by gently touching someone's hand that was near to her. When I myself noticed, I would take a deep breath or two, acknowledge to Patricia what I noticed, and remember essential things again, and remember honesty and personhood.

Her parents were co-conspirators with Patricia, actually, in this campaign for honesty. Anyone who might be tempted to refer to Patricia as "her" or "she" when Patricia was in the room, talking *about* her instead of *to* her, would be reminded instantly that Patricia deserved the respect of being addressed directly, always. This I came to trust in spite of the fact that when I first met her I did not think she understood much of anything, given her apparent unresponsiveness and apparent hearing loss. But I learned over my time of knowing her and her whole family and team, this necessity for respect and honesty. In her quiet way (sometimes maybe not so quiet!), her mother would often turn to Patricia and say something like, "I wonder what you are thinking, Patricia," bringing everyone back to the fact of Patricia's presence, the need for respect of her

personhood, the need for listening to Patricia herself. Sometimes her mother would add, after some time attending to Patricia and what she seemed to be communicating with her body, something like, "We (naming the people around the room) are here to talk about you, Patricia, because we care about you and we want to help you in the best way we can." Then our meeting would continue.

And humor. Patricia taught me to not take myself too seriously. Over and over. (Still a lesson I must learn daily, I admit!) There were many times when Patricia would break out into a huge smile at the most telling moments, as if to say, "What took you guys so long?!!!!" One time I remember in particular was when a number of us were gathered in the living room of her house and I was doing a training to help train some new caregivers. I began showing a video of myself communicating and eating a snack with a young Deafblind boy. Although Patricia was in the same room, her severe (Stage 1) Cortical Visual Impairment kept her from getting meaningful information from the screen, despite its size. And, there was never a definitive hearing test for her, so we never could be sure what she was hearing. Despite this uncertainty, it occurred to me that day, for one reason or another, that Patricia was missing out -- she did not have access to the video. So on an impulse I turned to her and said, "Patricia, I want you to be able to see this, too. Let's think what we could do. ... (I thought for a moment....). What about if two people act out what is happening on the video, right next to your wheelchair, so you can see and touch?" Almost immediately she burst into a huge grin and kept smiling and smiling, even laughing. We got some props that matched those in the scene on screen, and two women present imitated the tactile interaction that was being shown on the screen, up close and personal, so Patricia could touch them, could "see" in her own way. Patricia continued smiling and laughing for the whole time she was touching.

The message in Patricia's reaction to this simple accommodation to give her access was clear: "What took you guys so long?!!!" We were all smiling, abashed and delighted at Patricia's admonishment, and at her obvious pleasure at the fact that we finally "got it." She reminded us in her own inimitable way, just by her forceful presence (and by her family's insistence over many years) that she wanted to be taken seriously. How could I have forgotten? I still laugh inwardly when I remember this scene and how long it took me to learn to attempt to include her meaningfully. And how I have to keep learning this. Again and again, with each new person I meet, whether deafblind or not. Even in the smallest of ways. Thank you, Patricia. And thank you to her parents, who taught this to me and to all around Patricia. Every day, in many small ways.

I want to close by telling you about something you may have heard about that happened a few years ago now at a school in Georgia. Sadly, this situation is at least as relevant today as it was then, given recent events in this country.

In August of 2013 a woman named Antoinette Tuff was sitting at the reception desk when a very disturbed man with an AK-47 walked into an elementary school in Georgia

and announced his intention to kill all the children in the school and then to kill himself. A condensed version of the story: When Antoinette Tuff realized that the man was serious about his threat, she called 911 (the emergency number) and she also began to talk with the man. For more than an hour she communicated both with him and with the police outside (through the 911 operator).

She realized very soon that he was mentally ill (he told her that he hadn't taken his medication). And she began gradually to have a genuine conversation with him, connect with him as a person -- not out of fear (though she did feel fear, she later confessed!), but out of genuine empathy and what she described as "anchoring in the Lord." We each might have our own version of this language. (I myself translate this as a faith and trust in the basic goodness of people and in forces greater than our individual selves.) Ms. Tuff began to tell him about her own troubles in life: the fact that her husband had left her, how she had felt hopeless, even suicidal, but had gradually found strength.

When she began telling him about herself, from her heart, he began to have hope, to see a reason why he might not want to, or need to, kill himself or the children that day. When he told her his name, it turned out that his last name was the same as her mother's maiden name, and she told him so, saying, "We could be family." This genuine acknowledgment that she came to spontaneously and expressed to him spontaneously is all the more remarkable given the fact that she is an African-American and he is a white southerner. ("Were they descended from slaves and slave-owners?" I find myself wondering now.) He responded to her acknowledgment by trusting his connection with her. Eventually he became willing to surrender, to put his weapons down. She kept assuring him that he would be OK, that he hadn't yet killed anyone, and that he didn't have to kill anyone or die himself.

He asked her to go on the intercom and tell the teachers that he was sorry, which she did (at the same time telling them to stay inside their classrooms until the incident was over).

The part of the interview that moved me the most was, if my memory serves me right, near the end of an interview with her that was broadcast the next day by a local TV station. Someone asked her what made her able to connect with this man. She said, "My son is disabled. He can't see well. And he has a hearing impairment. He can't just go out and get a job like most people. It's hard for him. Life is hard for him." Tears fell down her cheeks at this point in the interview, and I could see in her face her deep care and compassion for her son, and her identification with his challenges. She said that she came to feel a similar concern for this disturbed man armed with weapons and self-hatred. She could see beneath his bravado and desperation, to the wounded and struggling young man underneath.

This woman was armed in her own way -- armed with compassion, and with her love for her own child, and through him for other children, and also for this disturbed man. Her son who, from her description, seems to be a Deafblind young man, seems to have played his own small, but not insignificant, part in this drama -- a drama that ended not with death, but in a surprising and life-giving way.

I think and feel that such stories, and such people, need not be exceptional. We at this conference happen to be somehow blessed (why not call it that?) with either knowing Deafblind people or being Deafblind ourselves. Deafblindness offers a very unique way of experiencing the world. And it asks of all of us to realize the ways we are interconnected. With each other, surely -- as this conference attests. And with the wide world. Science is affirming this from so many perspectives: we all live as part of a complex web of interconnections that includes not only all of humanity, but all ecosystems, and solar systems, and who knows what other possibilities?

If you wish to read a lovely description of the importance of this interconnectedness and the power of the small, and the possible resonance of each small action, I refer you to: <http://www.dailygood.org/story/1976/scale-in-the-story-of-interbeing-charles-eisenstein/>

However we each define and experience our interconnectedness, I have no doubt that nearly everyone in this field can attest, each in our own way, to the fact that each child and adult with this lowest of "low-incidence" disabilities has touched our lives in ways we might not have anticipated when we entered this field (whether we feel like we have chosen the field, or it has chosen us). Each person along the way has brought us surprises, moments, stories. May we each be grateful for all of these stories and people that have touched us along the way, and will continue to touch us into the future, as I surely am. And may we each allow these stories to ripple out into the world, aware that their influence may be affecting the world in ways that we cannot define. Ways that we cannot know. Ways that we might find to be surprising.... Who knows...who knows?