

## **FROM BEHIND THEIR EYES: A LIFE-LONG CAREGIVER ENTERS THE CARE-GIVING WORLD AS A CLIENT**

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In June 2015, after more than 50 years as a Child Care Worker, I had a fall in my home and suffered a traumatic leg injury. I have had a neurological problem all my life (“ ataxia”, which affects balance) and it got the best of me as I fell while turning on the ceiling fan. As I fell I somehow got all twisted up in myself, resulting in a broken femur, dislocated knee, crushed femoral artery, broken nose, and concussion. When I arrived at the trauma center they contemplated cutting off my leg as my foot was black. Very fortunately for me there was a vascular surgeon on the team and he did a vein/artery graft and saved my leg. I still have extensive nerve damage and spend more time in a wheelchair than walking. I was declared a “train wreck” by one of my Doctors. We all have names for those kids whose “injuries” from abuse and neglect make us uncertain that we will ever be able to help them. And in that Doctor’s face I think I saw that familiar look of uncertainty mixed with hopeful challenge that most of us have experienced as we anticipated the path ahead of us as we journeyed toward emotional healing for our most damaged clients.

I spent over six months either in the hospital, skilled nursing facilities, or home briefly with 24-hour Caregivers. They couldn’t replace my knee and I couldn’t walk until my femur healed which took five and half months. I got my new knee in November and was able to come home with a loving friend as my Caregiver on an “as needed” basis until I am able to walk. Having and paying strangers in my house 24/7 did not agree with me. Of course, for those of us who have worked in substitute care facilities, we spend so much time there it feels like “home” to us, and I wonder how often we remember that we are “strangers” to the residents, and they are well aware that they are not “home”. My very first job was in the “Children’s Receiving Home”, which was a large brick institution for teenagers, not children, and it was anything but a home. Do we think we can change the client’s reality with some fancy (but deceptive) word play?

My injury began a seven month journey into the care-giving world as one receiving, rather than providing, care. Although I don’t think I learned anything I didn’t know, on some intellectual level, I **experienced** what I knew in a way that gave me a renewed love and appreciation for all of the children and teens I have taken care of over the years. It also provided more than a little “guilt” for how often I may have acted like the Caregivers I became so uncomfortable with. My experience also set me on a kind of “mission” to tell Caregivers what I learned from my own journey, in the hopes that others will benefit from the insights gained from being “nobody” for over half a year. I learned that my injuries defined me for almost everyone who took care of me, and that who I actually was, apart from my injuries, was not particularly interesting to anyone. Now that I am home, although still quite disabled, and being cared for by someone who loves me, I am more acutely aware of what it was like to be cared for by people who saw their caregiving clearly as a “job”, and who saw me – actually not at all. That is, I don’t believe any of them actually saw “me”. And as soon I was discharged I would be replaced by another traumatic injury, or in our world, another “case”.

In June I was a “patient” in the intensive care unit. I wasn’t much trouble for the staff initially, since I was very heavily drugged and unable to communicate. I was a patient in a bed with tubes coming from multiple orifices. When I woke up for the first time I found that I was tied in restraints. Like many of our kids, I went ballistic, threatening to sue everyone, telling everyone I knew my rights, and demanded to know why I had to be tied to the bed. The explanation I was given was that, it was “necessary”. I was never told why and learned only later that I was trying to pull the tubes out. Or at least I don’t remember being told why in a way I understood. If this was the case it would have been helpful for them to tell me that I got an explanation that I might not remember. I never felt that I was a person, in the full sense of the word, in that none of the professionals were there to deal with me as a distinct individual but only as an “orthopedic case”. Even in my drugged state I remember being acutely aware that who I was didn’t matter to anyone there. It wasn’t until I began to come out of my semi-consciousness six days later and recognized one of my visitors for the first time that I was, once again, Lorraine. I don’t remember any of the hospital staff using my name. My friends told me they had imparted bits of information about me to the staff on occasion, but none of this was reflected in any of my interactions with them, which were always very impersonal and centered solely on my injuries.

Following my time in the hospital I was moved to a nursing home/rehab facility where for three months I became known as 106B – my bed number. I remember hearing people in the hall telling someone to go to 106B when my call-light was on. For the next three months I was, in addition to my bed number, “Fox, Foxy, Mrs. Fox, Miss Fox, Mrs. Lorraine, Miss Lorraine”, almost never just Lorraine, and to itinerant staff “Hello, or Hi there”. Not only was I almost never called by my name, I was never asked anything about myself except as it related to my physical condition. Did I have a bowel movement? Pain level on a scale from 1 to 10? How did you sleep? Is that all you’re going to eat? And, most frequently, I was not asked anything but told “you’ll have to wait, I’m busy”.

In my next skilled nursing facility I was Room 24, the “name” on my meal menus. Again, I was never asked anything about myself other than whether I had had a bowel movement, and pain level from 1 to 10.

The important thing I want to convey is that I was not treated badly. Everyone was kind and pleasant and I never experienced any kind of cruelty. Looking back on the experience, the cruelty was entirely unintended. Although everyone was always very nice to me, they were not, I felt, being nice to **me**, but to the patient in Bed 106B or Room 24. It’s hard to express how that impacts someone because it doesn’t seem unkind. There is something very profound about being treated well, but entirely impersonally, which I am guessing many of our clients experience. And like me, they are probably not sure how to talk about it because it doesn’t involve any overt unprofessional behavior. It just becomes what one learns to expect and I became very passive about it and accepted it without any anger. It is what it is. But I never meant that to be the experience of any of the young people I cared for.

God has blessed me in many ways but none more appreciated than in the number of friends and well-wishers I had. Having a visitor was the only time I felt a little more like “me”. But even then, I was more patient than anything. Very often I wondered about and empathized with those people around me with few if any visitors, who had become reduced to their bed numbers and

last names attached to the wrong prefix. My roommates' last name was Bell, and everyone decided that was her first name and everyone but me and one of the nurses addressed this 91 year old woman with five children as "Bell". She never bothered to correct them.

I was fortunate in that I've had many years to find out who I really was, but the experience was unnerving even at that. I was also very surprised to find that many of my long-time personal qualities started to change. I've never been a particularly patient person, but over the weeks I shared with friends how I noticed myself becoming "passive", because I realized that it wouldn't have made a difference whether I was patient or impatient in terms of a response. Having become in my development, a more assertive person I had learned to receive a different level of responsiveness. Now, suddenly in my later years that particular trait either did me no good or irritated people. I learned that passiveness and compliance were appreciated and attempts at assertiveness were received negatively. And who says you can't teach an old dog new tricks?

I'm home now and returning more to myself. But I have been reminded again how powerful one's immediate environment is in terms of developing personal traits and a sense of "self". I have new appreciation and concern for those people who had experiences growing up that did not provide opportunity for developing a strong sense of who one is, both positive and negative, strong and weak. I'm blessed because I have a strong sense of "self" to come home to: Not everyone does. I've often heard adults ask kids, usually when correcting them, "why do you act like that?" Now I remember why. We act in ways that are either encouraged or punished in our environments. I guess a better question for parents is not "why do you act like that?" but "what am I doing that is resulting in that kind of behavior?" Or, what did someone else do that resulted in this kind of behavior? We can't just tell kids that they have to stand up for themselves, but we can ask ourselves if we are creating an environment where standing up for yourself or asking questions is encouraged, and not rebuked, and not construed as "argumentative", which was my experience.

As I sat down to write this article, looking to translate my experience into something that might be helpful for kids I'll never meet, I thought back specifically to two kids who came into the crisis shelter I directed. Significantly, for the purposes of this article, I can't remember either of their names. I do remember both of their "presenting problems". The first girl I'm remembering made it a point to introduce herself on her first day by making sure I knew why she was with us. She had been "thrown out" of quite a few programs, and this was her claim to fame. "I suppose you know that I deck people", she said by way of introduction. "Specifically, staff people", she emphasized. I remember immediately going into my diatribe about how she wouldn't be "decking people" here, and constructing a contract with her about what we would do to help her, and what we would expect she would do to help herself when she got the urge to strike someone. I don't remember asking her anything about herself that was not related to her assaultive behavior. I never found out if she could sing, or draw, or play a sport well. I don't remember engaging her about anything not related to her "problem. In other words, I treated her the way people treated me when I was "the lady with the traumatic leg injury wearing an 'external fixator', which made people uncomfortable. The "train wreck".

The other client I thought of immediately was a client we had taken care of before who had been very popular with the staff. A "nice kid", we all remembered when her name came up. Her

social worker called to say that her foster home was “no longer available” and wondered if we had room for her. Everyone remembered her and agreed to accept her without hesitation. When she and her social worker arrived we learned why her foster home was no longer available: she had burned it to the ground. I remember how all of us were shocked and wondered how we could have been so wrong about her. We began our heavy conversations about her “arson behavior” and began drawing up a contract about what we would do to prevent such behavior in our facility, and what we expected her to do when she got the urge. What is clear to me now is that we didn’t “get her wrong”. She was **both** the nice kid we had taken care of earlier, **and** the kid who burned a house down. The first time around we missed the anger that would prompt such dangerous and dramatic behavior. However, this time around we began to focus all of our attention and conversation to her “fire setting” behavior, forgetting to engage with her about all of the wonderful parts of her we had seen before. She certainly was more than an “arsonist”, just as I was more than a “patient”. Would her life have been dramatically improved if we had taken the trouble to find out all that she was, and relate to all of her qualities and not just those prompted by previously unnoticed rage.

For the past seven months most of the people I see relate to me as the patient, since I am still in a wheelchair and can walk only a little and only with supervision. And incidentally, I am also seeing “supervision” through their eyes as well. There is one part of me that feels that no one wants me to walk on my own because they don’t trust me and fear I will get into trouble on my own. And, based on my history this is not a ridiculous thought. At the same time, I feel resentful of needing supervision. At the very same time, I feel grateful, knowing that because I am being supervised I will not get into trouble and will be safe. I have come to believe that many of our loudest complainers about “being watched all the time” probably host both of the feelings I experience: resentment mixed with a heavy dose of relief.

Even now, most of the conversation with me is about how I am doing physically, and very little about the parts of me not related to an injured leg. It has made me wonder how many of our kids would welcome a conversation completely unrelated to their “case”, or “presenting problem”, or “program goals”. And I don’t wonder why they don’t bother calling our myopic focus to our attention, having given up on being “seen”, or “known”, as I did. I have come to believe that we will have to take the initiative to have conversations about all aspects of who our clients are, not just those we know about now. We’ll have to let them know we are really interested, because I will not be surprised to learn that their journey through child welfare thus far might have convinced them otherwise.

One additional experience that caused me to “let go” of some aspects of who I am is the lack of privacy and modesty required in long term care. I have never been one who was comfortable being naked with other people, and I was equally uncomfortable having other people naked in front of me. I learned, beginning in high school how different people are in terms of their modesty or lack of modesty. Many people showering after a game of racquetball or in gym class, are perfectly comfortable chatting while getting dressed. I, on the other hand, preferred to be left alone while dressing unobserved. Neither way is good or bad, but is definitely a part of one’s individual comfort zone. Being “in care” means that you will experience a complete disregard of your personal need for modesty. Unable to walk, I was relegated to bed pans for over half a year, necessitating being cleaned up by whichever man or woman was assigned to

me. Gradually I noticed that my previous feelings about modesty gave way to resignation about being cleaned and showered and dressed by whichever staff member was on duty. I began to think of the group living situations I had spent most of my career either working or consulting in. I had, on occasion, given brief thought of what the clients must experience toileting, showering, and dressing in the presence of a large group of people who were not family. Now I look back and try to remember if I ever had a discussion of this aspect of group living with clients I worked with. I don't think I ever did. What part of me decided that this was an incidental part of group living and not a really significant one for many of our young people. Just as none of my caregivers ever related to this part of my experience and so I didn't mention it either, except in jest sometimes, I'm guessing our kids take our indifference to their feelings about personal modesty cause them to think there's no point bringing it up. It's too late for me to go back and have the discussions I should have had with my kids, but it's not too late for you. Tell your kids you were reading an article about a CYC who became a client and who wrote about her feelings about being regularly exposed to a parade of non-intimate others, and use this as an opportunity to give them a chance to talk about their feelings about this aspect of their experience.

Based on my experience in care, I would like to throw out a challenge to anyone reading this piece. I would ask you to keep track of the content on your conversations with your kids – whether in a residential care facility, or a foster home, or a special education classroom, or community based program. How often do you just sit down with a kid to find out who they are. Who are they totally? How much do we see all of them? Are we so busy looking for the problems we are being asked to help with that we forget to engage with them about parts of themselves that don't need help from us at all, but that they know are a big part of who they are. Do we even ask them “what are some things about you that nobody has asked you about?” Are there some parts of you that nobody here sees? We spend so much time talking with you about issues that are challenges for you, are there some things that you do really well and don't need any help with at all? What does it feel like to have people talking with you constantly about your “problems”?

What I learned from my experiences as a recipient of “caregiving” is that there is only one way to really find out who someone is and that is to talk with them. Ask them. Many things about us are just not apparent. Many parts of us are not related at all to the “problems” we are having. This is true not just for our child and teen clients, but for their parents as well. Families come into the system because of problems, and this tempts us to become problem focused rather than person focused. I am happy to note that many “strength-based approaches” are trying to remedy this myopic focus on weaknesses and limitations, but I want to throw something out for contemplation.

I had many of my Caregivers, doctors, nurses, aides, and physical therapists – give me lots of positive feedback during my rehabilitation. But I now realize that all of this “cheerleading” was still directly related to how I was handling my “problem”. I don't remember anyone saying anything positive about me that was not directly connected to why I was getting treatment. As a “patient”, their view of me – both in terms of injury and of compensating strengths – were focused on my need for care. And believe me, I had lots of needs for care. At the same time, there were things that were true about me that were completely unrelated to why I needed care, and these parts of Lorraine just never came up. Friends of mine told me that occasionally they

would tell one of my Caregivers something about me that was unrelated to my injury and treatment, but even when this was mentioned to me – which was almost never – it was quickly forgotten and never became part of our day to day interactions. After a brief mention that: “Someone told me you speak, write, have a Ph.D., have a dog and a cat, are funny, play the piano and ukulele, live in a retirement community close by, spent your whole career taking care of kids.....” These were never mentioned again and did not change their prevailing interest in my bowel movements and pain level from one to ten.

I wonder if this is true for us with our clients. I only know one way to find out. I invite any of you, dear readers, to ask. Ask your kids, teenagers, parents what their experience is **with you** of being seen and known as a whole person. Do they hear you praise them for their skills and competencies as frequently as they hear you address their problems? Do they believe you even know ten things about them that are unrelated to why you came to know them as a client? Or even five things.

It’s too late for me to take my powerfully reinforced insights into my work with kids. But it’s not too late for you. Think of a time when no one really knew or cared who you were. What was that like? Remembering the experience will help you help your kids when they feel like strangers. Share these experiences with your kids, and ask them to share their experiences with you.

“We’re all just walking each other home”, said Ram Dass.

As we walk together, let’s find out who we’re walking with.