

"Lillian's Lessons"

By Joan M Fenske RN, MS, PhD

"Kenny knows his name". Lillian eagerly greeted me by announcing another of Ken's achievements.

"Hi Kenny" she called across the room.

Although Ken's back was turned, he responded with a squeal of delight. Each morning, as each child was unloaded from the bus's wheelchair lift, Lillian, and two Education Aides, greeted each child, individually, by name. After responding, each got a "high five". Was Kenneth responding to Lillian's voice or to his name? This became another mystery of Kenneth's life. I was satisfied with the idea he knew his name no matter that to us his name was Kenneth. That Kenneth had a new name and a new life, so be it, he obviously was happy.

This day, I'd had come for lunch, to participate by feeding Kenneth. Lunch was delivered. It looked like "airplane food".

"What's this?" I asked Lillian.

"No school cooks. The school's budget crisis eliminated their positions. Now the school district contracts out for lunch service. That includes lunches for students here at Ludlow".

"But how do you feed it to them?" I looked at trays containing pizza and burritos. The trays included other menu items I knew none of the students with disabilities could ingest.

Then I noticed the blender. Each of the lunches had to be run through the blender so students with swallowing difficulties could eat.

"We always add water or juice to the mixture to smooth out its texture and make the mixture less dense. It takes a bit of time to prepare all 12 lunches", explained Lillian. "We'll augment their lunch with other

Classroom Management Series - Lillian's Lessons

food, like yogurt, purchased from classroom funds. We also make sure each student drinks lots of water and is well hydrated”.

“Is any consideration given to each child’s need for a special diet? All these kids have special diets. Most have problems passing their bowels and require bowel care. Is pizza and burritos the best food choices for them?” I asked. “Doesn’t the school district have a Nutritionist?”

I was amazed children with developmental disabilities were victims of cuts in the school district’s lunch program. Most of Lillian’s kids were medically fragile. Their medical care was regularly monitored and paid for by Crippled Children’s Services (CCS) and Medicaid.

“Could you write a letter?” replied Lillian.

Lillian introduced me to the concept of advocacy and the power of a parent’s input. Multiple issues needed attention, but I always looked to Lillian for assistance in prioritizing them. Too many ill informed letters were as bad as none. Lillian insisted good advocacy required in-depth understanding of each issue.

Lillian presented me with another of Kenneth’s achievements: his latest mastery of skill.

“Watch Kenny as he pays ‘attention-to task’. He has the best class record,” she said.

Not well versed in special education terms, I awaited Lillian’s explanation of “attention-to-task”.

“I’ve positioned Kenny on his stomach over a foam bolster. He has an infant busy-box placed at a 45 degree angle to his face. It’s contained within a low-sided cardboard box. The busy box is secured so he won’t knock it about as he manipulates each action location. He will lie there, working on his busy box, up to an hour if we’d allow it. He’s learned how to make each trick work. In fact, I’m searching garage sales for new busy-boxes.

Lillian was always on the prowl, searching garage sales, looking for classroom supplies and equipment. Styrofoam pillows and pieces were excellent finds. My solution to any of her expressed needs was to simply purchase the desired item. This was not an option for Lillian as she strictly adhered to her classroom’s budget. Her dedication to enriching her student’s learning environment brought tears to my eyes.

Lillian was “a good person”. If it weren’t for Kenneth, I would not have found each “good person” I entered on my imaginary list. Lillian immediately bounded to the top of my list. Searching, I had not found a better descriptive term for all those we encountered. “good people” unselfishly committed themselves to serving the disabled. Lillian deserved gold stars, hero badges, top billing, pledges of allegiances and all the accolades I could think of.

Classroom Management Series - Lillian's Lessons

Assessment of skills and testing preceded each annual parent-teacher conference. Annual conferences included Kenneth, Lillian, parents, Hillside Home's Grace Luke (Ken's foster parent as Kenneth's was in an out-of-home placement) the School Nurse, plus other assigned school district specialists including Nutritionists, Occupational and Physical Therapists and Language Specialists.

Kenneth had never been evaluated for language skills. He was referred for testing. A special conference was arranged between the Language Specialist, his Social Worker, his Special Education Teacher, Foster Parent, and us, his parents.

Kenneth's Language Specialist was very positive. Over time we'd become inured to high hopes that rapidly disintegrated as Kenneth's true developmental status emerged. My ensconced attitude was the more attention Kenneth got, the better. If that meant testing and retesting to sort out Kenneth's potential, so be it.

The moment we walked into the conference room, I suspected Kenneth's test outcomes.

The Language Specialist was a pretty, young, vivacious woman, eyes sparkling and bubbling with enthusiasm: raw meat for Kenneth's flirtatious ways. I intuited the con job Kenneth had accomplished. Patiently, we listened to the test results with a "show me" attitude.

For those with cerebral palsy, who are unable to easily and intentionally move their arms and hands and have difficulty speaking, a new testing method relied upon eye movements to signal comprehension. In other words, several picture cards were held up in front of Kenneth's face and eyes. He was asked to locate the dog from among two other picture cards. If his eyes looked at the right picture three out of five times, he would be given a passing grade.

Kenneth loved looking at the Language Specialist. I was happy they non-verbally communicated but unconvinced Kenneth knew a picture of a dog from a tree. Lillian quietly included the test results in Kenneth's Special Education folder.

Still, I was convinced that Kenneth could obtain communication skills. Lillian recognized his "squeals of delight", or the sounds of "sadness from his heart". He expressed displeasure and yelled with pain at appropriate times. Lillian stated he "never cried wolf". If Kenneth cried out something was wrong, something was troubling him. Often, it was his bowls. After our experience with the Language Specialist, I hesitated to pursue Kenneth's communication skills but, with Lillian's tutoring, I learned how to discuss my interest in furthering Kenneth's skills in terms the Language Specialist and other education experts accepted and understood.

Surprisingly, I crashed into competing theoretical points of view about language development. Who knew the education community firmly believed that cognition preceded language? That meant Kenneth needed to learn to identify a real object, (like a fire engine), relate it to the concept (and meaning) of a fire engine in his mind, then transfer his understanding of the concept to a representative symbol; that being a picture of the fire engine, then attach a word to the symbol and use the word (language) appropriately.

Classroom Management Series - Lillian's Lessons

Such a learning sequence was not going to happen: at least not in my understanding of Kenneth's future, given his incapacitating mental retardation.

Lillian provided insight. From her experience, she cobbled together a possible plan. I was convinced if Kenneth could be trained to push the right button, receive a treat as he succeeded in pushing the right button, he would be able to communicate a few basic needs. I termed this training as "rat psychology".

Kenneth could learn to communicate, but not by using language to do so.

Teaching this method of communication was not a component of the school district's language and speech therapy curriculum. No referral resources were available, so outside funding was obtained to support Kenneth's Individual Education Plan's (IEP) communication objectives and goal.

Lillian's lessons increased my understanding of the time and expertise required for each of Kenneth's multiple issues to be identified, then articulated to his IEP committee, prioritized, assessed, tested and evaluated. It took time to procure fiscal resources, institute a plan of action then monitor progress: assuring all activities was proceeding according to the approved written plan. There seemed no end to the issues Kenneth needed addressed.

"What are you all doing?" I asked Lillian one morning. All the kids had their feet in buckets of warm soapy water. Lillian and the Education Aides were going from bucket to bucket soaking and scrubbing 12 sets of feet.

"Because they don't walk on their feet, their feet build up dead skin and calluses. This makes their feet sweat and smell impeding body hygiene. We consider it a health hazard. Nobody likes working with a smelly kid." Lillian smiled at my non-verbal reaction.

One day, during the fall term, I popped in to the classroom unannounced. No Kenneth was on hand. Thinking he might be back at Hillside Home, ill, I looked at Lillian in distress.

"Kenny had a prior engagement. He's over at the high school". Lillian laughed at my surprise.

Lillian was always up to something, taking advantage of all opportunities to expand her student's world. Well versed in state and federal law as well as school policy, she quietly exercised her knowledge; leveraging students' educational needs with school district resources. Special Education administrators knew they could expect a memo and visit from Lillian whenever the teacher's newsletter announced innovative initiatives. Her position was that innovative initiatives applied to all students including those with developmental disabilities.

"If you don't ask, it won't happen" was Lillian's philosophy.

Classroom Management Series - Lillian's Lessons

“High school students obtain education units for community service. Participating with students with developmental disabilities, in our classrooms, qualifies as community service. Kenny took off with one of the football players to attend football practice. He had a choice between going off to the library with a sophomore girl or to football practice with a senior boy. Kenny chose football practice”, she said.

Offering choices to children with developmental disabilities was a key concept in Special Education. So much was simply “done” to children with handicaps they became passive. Unable to feel the power of choice in their lives, they became ever more dependent. Offering simple choices of which shirt to wear, what food to eat, what activity to do supported each child’s emerging sense of self.

Lillian knew Kenneth’s avid interest in the opposite sex. I suspected she manipulated Kenneth’s choice.

“No, no”, she replied. “Mike chose Kenny. Kenny never had a chance; yelping with joy as Mike wheeled him out of the room. The football guys think Kenny’s wheelchair is really cool; all that leather and chrome”.

Lillian’s energy was contagious. Her students experienced life out in the real world. I wondered about family outings that might include Kenneth. Worried about undertaking such a responsibility, fearing potential disaster while seeking new adventures, Lillian encouraged me to “go for it”. Lillian assisted me plan the necessary logistics. I always discussed my ideas with her. She never immediately fixated upon the negatives. According to Lillian, Kenneth could go to Disneyland, could see Christmas snow, and could go RV camping in State Parks. It was possible to do most everything!

Lillian’s teachings encouraged us to get Kenneth out and about in the world. We’d find strangers who were readily accommodating. Getting stuck while placing Kenneth’s wheelchair in or out of the car, someone always initiated, unsolicited, a helping hand. Kenneth readily responded with thanks, awarding them with his handsome smile.

“Hey, we’ve having a party,” announced Lillian. “Glenn is ten years old”.

Glenn was Kenneth’s fellow resident at Hillside Home and two years older. Glenn’s developmental disability resulted from measles contracted when he was an infant. Glenn and Kenneth were buddies and could be found sharing the classroom’s waterbed each day. Taking a break from being wheelchair bound, they wiggled around. The waves they created made each other giggle. A birthday party would be a celebration of their obvious friendship.

Lillian’s classroom was a happy place to be. Opportunities to celebrate ranked high in importance in Lillian’s classroom. Birthdays, Spring Break (unauthorized Easter bunnies), Halloween, Thanksgiving, St Patrick’s Day, President’s Day; all were opportunities for fun. Cakes were always involved. On Mothers’ Day, Kenneth made me a traditional clay handprint. For Christmas, a sparkling star made from tongue blades and his picture hung on our tree. Once, unannounced, Kenneth’s father received a card with Kenneth’s “face-painted” picture grinning away at the camera. Planning for parties involved everyone, teachers, bus drivers, Education Aides, parents: even high school students, lazing about, were recruited.

Classroom Management Series - Lillian's Lessons

Another of Lillian's lessons was learned: life did not need to be grim. Birthdays and holidays were great ways to build relationships, planning parties provided opportunities for family and friends to work together. Just because Kenneth was different, disabled, penance was not due. Life went on: daily routines had room for fun and games. Even Kenneth could finger paint wall pictures. Let the good times roll!

"I need a favor", said Lillian one day.

"Anything you want", I replied.

"The School Board plans to cut Development Center funding. Board members misunderstand how Special Education functions for students so medically fragile and developmentally compromised. Many think our Development Center program is merely a babysitting service. Would you write a letter to the Board describing our curriculum and how Kenny benefits from attending school?"

"Yes", I said.

As Lillian presented me another opportunity to exercise my advocacy skills, I considered my assignment as I sat down to write. If I were a Board member, what essential information did I need to know about the Development Center? What was being taught to Ludlow's students? Were they truly learning? What made the Development Center's program curriculum different from "babysitting" activities?

Board members knew each child had the legal right to a "free appropriate public education". They knew individuals with developmental disabilities required their developmental deficits assessed, then accommodated, to attain learning readiness.

Board members had limited understanding of how children with developmental disabilities learned. It was only with Lillian's lessons had I gained comprehension.

Who was being taught? What was being taught?

Who was learning?

Was Kenneth really learning?

Kenneth was correctly positioned upright in his wheelchair. Thus he encountered his learning environment upright, face-to-face and comfortable. Kenneth obtained prescribed individualized arm braces, freeing his arms and hands to engage and learn new behaviors. Identifying the proper prone position, lying over a foam booster, was established as his most effective and beneficial position. In this position, Kenneth learned Special Education skills termed "cause and effect" and "attention to task". Correct positioning was an essential precursor to master developmental tasks.

Classroom Management Series - Lillian's Lessons

Kenneth's language skills were assessed. Finding ways for him to communicate became an integral part of his curriculum and a Special Education responsibility. His vocalizations had meaning and were interpreted. Kenneth gained greater command over meeting his needs.

Daily school attendance socialized Kenneth, teaching him to interact appropriately with others including teachers, caretakers and fellow high school students. Kenneth readily elicited responses from those about him. He learned to control his environment with his sunny personality and generous smiles. Kenneth functioned positively, out and about, in the community. As a family member, he fit right in, without causing undue attention to himself. Kenneth was included as a family member as we visited restaurants, stores, and vacation destinations.

Learning how to speak the language used by Kenneth's multidisciplinary IEP team, we became adept in using Special Education principles and concepts to advocate for Kenneth's on-going development.

Kenneth learned how to learn, acquiring new information and skills at his own pace.

Kenneth was learning!

Caretakers, Special Education Teachers, Education Aides, Speech Therapists, Nutritionists, Occupational and Physical Therapists and Administrators, all researched and learned unique interventions specific to Kenneth. Thus he achieved measurable behavioral objectives.

As parents, as part of Kenneth's Special Education curriculum, we learned how to parent our medically fragile child with developmental disabilities. His care no longer needed to be delegated to professionals.

We successfully participated in providing instruction for our unique son.

We learned to appreciate him as an integral family member and see his essential human value. He was a worthy human being. Kenneth easily developed positive relationships with those about him. Seeing the joy Kenneth provided, reflected by others, we honored Kenneth as our son.

Public education prepares children and youth to enter society: to be productive members of society, be citizens and further societies' goals.

School Boards allocate scarce resources. Investing scarce resources in students with the most potential at first seems a wise course of action. However public education does not discriminate by predetermining an individual's predilection or proclivity for learning. Or discriminate by predicting an individual's potential benefit to society. All are equal under the law.

Classroom Management Series - Lillian's Lessons

Ken was learning. We were learning. His caretakers were learning. His educators were learning.

Kenneth was a citizen, and his role, as citizen, was to further societies' understanding and acceptance of the disabled by demonstrating his unique handicap did not hinder him participating as a valued member of society.

As a family, we recognized feelings of pride. We were proud of Kenneth.

What an unexpected experience!

Early on, all expectations of being proud of Kenneth were put aside. The idea we'd feel pride in Kenneth's accomplishments never occurred. We accepted, as truth, our son with developmental disabilities wouldn't "measure up".

But there it was; we were proud of Kenneth, his ability to learn, his measurable accomplishments and his ability to elicit love from those who cared for him.

We were proud of Kenneth. This certainty was achieved by his public education!