

CHRISTIAN AND HIS INTERVENER

This article is written by Melanie Knapp. It describes how her son Christian benefited from having an intervener. Melanie is currently the secretary of DBMAT and is actively involved in expanding the use of interveners for people who are deafblind.

INTRODUCTION

There are people that come into your life for special reasons. Sometimes, we don't understand why right away, but I have learned to accept that they are here not to change who you are, but to enhance your life and to teach you.

Honestly, I will tell you that I have had an emotional ride putting together this story about my son, Christian. I have chosen to share his story for one reason. I strongly believe in the "Intervener Model". I am committed to helping deafblind children in whatever forum I can.

Christian had many obstacles, both physical and psychological. Gary and I had many things that we had to struggle through and overcome throughout the years. Ultimately, this is really the story of Christian and Ann. Ann Bielert was Christian's intervener during his last three years at his high school. Through my words, I hope that their story can be a testament of what can happen when a deafblind child has the right program and support.

I believe Christian chose Gary and me to be his parents. I believe that he spent years teaching us to be patient, to have understanding for those who needed it, and motivated us to work for him and to fight for what was right.

Through Christian's struggles and strife, he inherently became my teacher. I have him to thank for my successes and the wonderful people I have met through our journey with deafblindness.

Christian died suddenly November 3, 2005 at the age of 25 years. He will always be remembered as "The Great Motivator" by our family and the people who knew him.

WHO WAS CHRISTIAN?

Christian's plan was to join his Mom, Dad, and older brother, Landon, July 5, 1980, three months sooner than was expected. He wasn't ready to move in to the house yet, so he made his home in the hospital for the next two years. I imagine that Christian had enough of hospital life by the end of those years, and thought he might try the family life. We welcomed him home, along with a truckload of hospital equipment. During the next 23 years, our family lived a unique existence.

Christian was a stubborn smart young man with a crooked grin and a wicked sense of humor (Knapp humor).

Christian could make me laugh and cry in the same moment. Our time together ranged from just sitting, doing nothing; to a learning experience (as long as he thought it was fun). Such menial tasks considered by others, such as learning to put his own socks and shoes on, were milestones for Christian. Each small accomplishment never went unappreciated.

Christian was totally blind and profoundly deaf, but extremely perceptive. He knew where you stood before you knew where you were standing. He walked mostly with assistance/sighted guide. Christian spent many hours trying to convince his O. and M., Michael, and his "intervener in training", Rodney, that he didn't like his cane. They spent even more hours adjusting his cane, only to be dismissed by Christian.

BEFORE THE INTERVENER

I have to go back to his high school days to tell you the story of a young man who a few thought couldn't learn, and others knew he could. With the right program, our son flourished and continued to learn until the day of his death.

It was March of 2000. We were sitting at his high school in an ARD. We had done this so many times before. But this time was different. This particular day would change our lives forever.

Christian had some good solid years behind him in school. . His program at the Middle School was targeted for communication and purpose. He was in a rich environment that had been supported by the Outreach team at the Texas School for the Blind and Visually Impaired. His calendar system was set up at home and school and Christian was getting "it".

What happened after he moved to High School?

I started hearing stories about what was happening {or not happening} at his high school. His calendar box was being used as a file cabinet. Someone told me they didn't know Christian could walk, because they had only seen him in a wheelchair. Each time I visited the school, he was seated in the same blue chair, pushed up in front of the television set with the other classmates.. He began to bite and scratch himself. They called it a behaviour problem. Christian was not the one with the problem.

We had been concerned that Christian had the same IEP goals year after year. Not only was he not making progress at school, he seemed to be regressing. I knew how smart Christian was. I also knew he needed to be taught a very special way. He needed his calendar box and he needed routines. It broke my heart to hear what his life was truly like at school. But, at the same time, it made me angry, and when "the momma ain't happy....ain't nobody happy". We had to change things for him.

Our first plan of action was to ask that TSBVI Outreach come to the school and do an assessment and make recommendations. They came. It was like starting over again. The deafblind student is unique. Christian was unique. We persevered.

Months before the ARD, Christian had been a focus student for Dr. Jan Van Dyke in Austin, Texas for a workshop for Interveners. My husband and I were very frustrated with his school, and after being at this workshop, I knew Christian's life could be better.

It wasn't that Christian, Gary, and I were there for the workshop that fascinated me. It was the "Interveners" that were in the audience. Who were these "Interveners"? What role do they play with a deaf blind student? And how could I get one for Christian? It was as if someone knocked me over, and when I stood up, it was all so very clear.

After attending Dr. Van Dyke's workshop, I read everything I could about interveners. Gloria, his VI teacher had attended the workshop as well. She was a vital component for gathering the information so that we could introduce the "intervener" model at our next ARD. I was very excited. The concept of having a one on one experienced (in deafblindness) person working with Christian was an answer to my prayers.

We had tried to incorporate his routines and communication system with only his classroom teacher. It became obvious that if Christian was to be successful and to meet his IEP goals,

modifications were necessary. Karen Buchine, Teacher of the Deaf, worked with us on modifications that would take place in the classroom. The program was designed to fit Christian specifically. We knew that in order for Christian to learn, he needed:

1. Provide a high degree of consistency in presenting new information by having only one person introduce new sign vocabulary.
2. Provide experience-based one-on-one instruction to supplement and/or introduce group instruction.
3. Provide frequent comprehension checks.
4. Provide one-on-one instructional support on a daily basis through a single designated staff member.
5. Present communication through sign language presented one-on-one by Christian's designated staff member. Staff member will then teach other personnel specific signs to be used with Christian.
6. Adapt manual communication form by:
Substituting alternative signs/gestures
Tactual signs
Hand tracking
Co-active signing
7. Present signs tactually.
8. Use calendar box system for receptive and expressive communication and structuring of daily routines.
9. Utilize desktop assistive listening device provided
10. Provide a predictable environment with daily routines.

So on that day in March, as I looked at the faces sitting across the table from me, we prepared to educate the school about interveners. They had no idea what an intervener was and said so. We had brought all the information we could get our hands on and presented it to them. We must have made some kind of an impression, because the meeting was tabled. We would meet again in a few weeks and work out the details. It was exciting. I felt like we had made a real breakthrough. I couldn't wait till the next ARD.

It wasn't until May till the ARD committee met again. Gary and I arrived and took our seats. It was after school, so Christian was seated in the conference room with us. Eventually everyone made it in and seated. I remember feeling anxious about getting started. We all chatted for a few minutes. The meeting was brought to order. The ARD committee agreed that in order for Christian to meet his IEP goals that a one-on-one aide would need to be in place.

The next thing I remember hearing, was the Dept. Head of Special Ed at our school say to me quite casually that she had already asked around and "no one wants to work with Christian". I was upset. Not only for how she said it, but also I knew the aide HAD to come from the campus. There had been several weeks go by between ARDs, and this was the first time it was mentioned. She went on to say that she would see if anyone else would be interested when school started the following fall semester. My mind stumbled as I listened to what she was saying. I knew an aide would need training, and we had planned for that summer to be a training period prior to the 2000-2001 fall semester. She added insult to injury by asking us if we realized that the one-on-one aide for Christian would be taken away from one of her other programs. She rambled on, but I didn't hear her anymore. I did hear the raised voices of the other people in the room trying to hush her.

All the years of frustration at this school swallowed me up at that very moment. I looked at this woman through tunnel vision. I was a mama bear backed in the corner of that meeting room. This woman, unwittingly, had lit the fire under me that had been flickering for years. In retrospect, I have to thank this woman. Her callous unprofessional behavior brought us to another place in our lives.

It was apparent to Gary and I that this high school was not the ideal environment for Christian to excel. Another ARD was needed immediately. I had been devastated by this woman's attitude, and had immediately filed a complaint with the Special Education Dept. in our school district. The Assistant Director of Special Education listened to our complaint, and without delay, assured us that they would be able to find a willing person to work with Christian even if they looked off campus. We were advised at that time if we chose to change schools, we could. She came and presided at our next ARD. We were able to complete the ARD process, and at that time request for Christian to attend another school.

I remember how sad I felt to remove Christian from his home school. This was the first time that his brother, Landon, and Christian had ever attended a school together.

DULLES HIGH SCHOOL

The fall of 2000 was a new beginning. We had found a person with a willing attitude and a desire to work and learn with Christian. I had visited the new school and had been well received. I was nervous, but optimistic about the future.

I worked a full time job as a nurse, so I had the flexibility of working hours in the evening. I would always be available during the day. Gary owns his business, so he also could be available at any time. We knew this would be a "team" effort. It would take a "village" of support for our son.

For the last four years, not much had been expected of Christian at school. His days had consisted of mostly sitting. It was a stagnant boring existence. He was older now. He had a long memory of what his life at school had been like. I can only imagine how frightened he must have been. He had been moved to another school. There were people that he didn't know, and didn't know him. He had no idea what was expected of him.

We had Christian's calendar box at home. We knew that setting one up at school would not be entirely foreign to him. He had a few signs that we used at home in correlation with symbols in his calendar. He did understand some signs, but had not initiated any formal signs. We mostly anticipated his needs. Christian still wore diapers. We had bowel trained him, but without support from his school, we never could get him bladder trained. Christian was extremely tactually defensive. He had trouble trusting strangers. He was self abusive. This had improved some with medication, but he still had issues with scratching his face. He also had issues with oral motor skills. He was very sensitive around his mouth. He didn't chew, so all of his meals were blended and each bite was accompanied by a swig of milk.

Unfortunately Christian's first year at Dulles was disappointing. The aide working with him had no previous experience in deafblindness. Her willingness to learn could not make up for her inexperience. She had tremendous support from Craig Axelrod from TSBVI, Christian's VI teacher, Karen Buchine, and of course Gary and me. It did not seem to be enough, and ultimately another year would go by without proper programming.

During one of Christian's transition meetings two years prior, Craig Axelrod and David Wiley, from TSBVI had come down to our home. We had been told of a one-on-one aide working in the school district with a deafblind student at the elementary level. The term "intervener" was

not used in our school district. We received permission to observe Ann and her student. We had been told that Ann had been working with this child for one school year. When Ann had come into her life as an “intervener”, this child had gone from spending her days laying on the floor in the classroom, wearing diapers, and a diet of pudding to... walking without assistance, using the toilet on her own, eating a bowl of cereal which included her participation of removing the milk from the refrigerator and pouring herself. She was also reading black and white large alphabet letters. She was using a calendar box for her routines. I could see the anticipation on her little face when she and Ann “talked” about their next activity. This little girl, because of Ann’s intervention, had blossomed. Her spirit was ignited. I remember that day well. I also remember thinking how wonderful it would be for someone like Ann to be working with Christian.

ANN AND CHRISTIAN

Some say that dreams can come true. For Christian, his next year at Dulles, was indeed just that. Our dream included not only his program that we had worked so hard on, but the right person to implement the program.

Christian was 21 years old when he and Ann met. In Texas, Christian was allowed to attend school until he was 22 years old. Ann would have one year with Christian. We were unbelievably excited, yet cautiously optimistic. Ann admitted that Christian was the oldest deafblind child she had worked with. She had ten years of experience working in our area as an intervener. Her experience, her reputation, and her love for what she did were all evident when she became Christian’s intervener.

Gary and I knew we had been given a “gift” of Ann. We were determined that Ann would have every tool she needed to help Christian.

I had come up to school his first morning to talk to Ann about Christian, and to show her how we fed him. She had a lot of enthusiasm and learned within minutes Christian’s feeding routine. I know we were both nervous. We both had expectations, and neither of us was sure how this would play out.

Ann started a log that she wrote in every day to let us know what Christian’s day had been like. Gary and I would write back with what he had done at home. These logs became such an important piece of Christian’s progress. We spoke on the phone often. I came up to school often. I felt welcome there. Christian was in a transitional classroom. A lot of the kids had jobs to go to. His classroom teacher was very supportive of Ann and Christian. She encouraged Ann to “do her thing”, and was there when Ann needed her. Christian began developing relationships with some of the other students. Ann taught them to approach Christian’s hands to say hello. I remember Ann telling me that she finally got Christian to tolerate a small vibrator. He would hold his feet up so Ann would vibrate them. He enjoyed it. One of Christian’s new friends wanted to try, and before you knew it...there were 3-4 other kids who wanted to sit with Christian and play with the vibrator. Ann wrote me that one day, most of the class had a “vibrator” party. As time went on, Christian’s friends were given sign names and symbols. Christian eventually was able to recognize them with only their sign name.

Ann, Gary, and I communicated on a daily basis. We either wrote each other in the log, spoke by phone, or in person at school. Early on, Christian and Ann spent a lot of time getting to know each other. Ann and I spoke about his previous few years at school, and how Christian needed to adjust to a busy day. She wrote me on September 27, 2001 after one of our talks. “I looked at

some things differently. I am one long activity that has entered Christian's life." I laughed when I read that. Christian had "his way" of letting all of us know when he needed a break! On that same day, Ann wrote "Christian walked from the bathroom to his calendar by himself". That was the first time Christian had ever walked alone. On October 10, 2001 she wrote "Christian walked 284 steps alone on the tennis courts today". I was so proud of my boy. Christian was also beginning to understand more signs. Ann wrote that she had signed "bathroom" to him, and he stood up and walked toward the bathroom.

By the end of the fall semester in 2001, Christian had made huge strides. He was loading his calendar box in the mornings and afternoons. He understood his routines and it was apparent that he understood many signs. Christian had begun to sign some words: "vibrator", "eat", and "walk". Four months had gone by and we had only a few more months of school before Christian would graduate.

I asked Ann to share some of her memories of Christian for this story. She wrote:

"I have so many wonderful memories of Christian. A really happy memory that comes to mind involves the first time he signed "mom". Melanie (his mom) was already in the room, but Christian didn't know she was there. Melanie and I both looked at each other and I know we were thinking....it was surreal....did Christian really sign "mom"? She had tears in her eyes and I had tears in my eyes too. I know it was a tremendous experience for Melanie to see Christian sign "mom" for the first time. It was for me."

"Remembering playing kickball outside with Christian's friends and Coach Rosenbaum on cool windy days brings joy to me. He loved to run, run, run.....then stop....then wait, wait, wait...then run, run, run. It was fun for me to sign for Christian to run, stop, and wait...and then see Christian smile and laugh. I remember the huge smiles he gave from the sign for "waiting"."

"It was really good for Christian and for me when he first started walking with other friends. I remember a red-haired girl was one of the first students Christian walked with. They would walk around the gym during P.E. I could tell Christian really liked being with her. It was great for me to see the two of them walking together, and it also gave Christian a break from walking only with me."

"I remember when Melanie told me about the first time Christian signed my name. She told me that Christian picked up my symbol (a ring) from his calendar box at home and signed "Ann". He did this before coming to school that morning. It made me so happy to know that Christian cared enough about me to think of me.....and sign my name."

Christian was finding his way out of his dark and silent world with the help of Ann. He literally flourished before our very eyes. All of us involved in Christian's education believed that this was only the beginning for this intelligent young man. No one could deny that fact that Christian was receiving the appropriate program for him as a deafblind person. The proof was right in front of all of us.

Gary and I did not want to face that this school year would end. Everything that we worked so hard to get for Christian would be over. We could not give our son this "life", and then have it

yanked away from him. He proved that he could do this. It was up to us to make sure that he had every opportunity to continue to grow and learn.

We began our investigation of what we needed to do for Christian to stay in school. All we wanted was to make up for his “lost” years at his previous high school and for him to stay at Dulles and have Ann continue to work with him. Sadly, we were told that Christian “ages out”. He would not be allowed to continue after the school year ended. I could not hold my tears back as we sat in his ARD. I knew these professionals. I knew that these people that sat in the room on that day felt the same way that Gary and I did. They had seen the “miracle”. Their hands were tied. We were heartbroken.... but not defeated.

Gary and I had a long talk. We didn’t have a lot of money, but we knew that our next step was the right one for Christian. We hired an attorney. We knew that our only way of getting through to the district was to file a law suit. This is not what we wanted to do, but Christian needed us to. We prepared ourselves by vowing to each other that we would do whatever it takes for Christian. We knew we were right in our belief that Christian deserved to finish what had only been a beginning.

Our case never went to court. The Director of Special Education in our school district called Gary, herself. Our case had been reviewed and Christian would receive two more years of education. Within a few weeks, we again sat in an ARD meeting. We would stay at Dulles, Ann would be his intervener, and the “miracle” would continue to unfold.

The next two years went by too quickly. Christian and Ann became a “model” for interveners and deafblindness. Christian thrived with his understanding of tactual sign. Gary and I took sign language classes. Ann, Gary, and I became strong accomplices for Christian. We worked in sync with each other daily. We often spoke about the importance of our relationship and our communication and how much it helped Christian. We knew that what Christian learned at school was critical to include at home as well and vice versa. We worked on building a “bridge” between his school life and home life.

Ann continued to nurture Christian’s friendships at school. Chris was his best friend. He would meet Christian in the morning and walk him into the class. Ann had taught Chris some signs to talk with Christian. Ann shares this memory between the two friends.

“I loved seeing the friendship that developed between Christian and Chris. I could tell that Christian was so comfortable and happy when he was with him. They would walk together to lunch, and they would walk together in the afternoon to wait for Melanie to pick Christian up after school. While waiting for her, Chris would sign “wait for Mom”. I know it made Christian happy that Chris learned to sign and that he learned about Christian’s calendar box. It was good for Christian to feel he was understood and to have Chris as a friend. There was the time that Chris and Christian took off from the classroom. For a moment, I was frightened.....because they left without me. I went out into the hallway and saw Christian standing with Chris while talking with a girl he liked and some other kids. It was the best feeling seeing Christian interacting with other friends.”

Ann and Christian had been going out into the community. Christian would shop at the grocery and other stores. He had a few favorite places that he liked to eat....well... eat the chocolate dessert. Ann shares her memory with Christian at the Burger King.

“Sitting at Burger King drinking chocolate milkshakes brings me to another wonderful memory. Side by side in the booth, Christian and I could feel each other’s arms when either of us would take a drink. One time, we ordered only one milkshake....so I took some of his. I know Christian REALLY wanted all of that chocolate for himself. He noticed there wasn’t as much in the cup as usual. He knew there should have been more....he wanted more....so we got another shake. Sharing that time with Christian is something I will never forget.”

We had been supported by the Texas State School for the Blind and Visually Impaired Outreach for years. Craig Axelrod worked closely with Ann and the other team members ensuring that Christian had every tool he needed to learn, including training for Ann, Gary and me. Craig was a friend to us, and to Christian. During one of Craig’s visits, Ann, Christian, and Craig had spent the entire school day together. Ann writes about that day.

“The time that Craig came to be with Christian and me was the best day. We went to eat at Luby’s, and of course....Christian had his favorite, chocolate cream pie. It was a beautiful sunny day. I remember sitting outside by the tennis courts on a bench with Craig and Christian. They were discussing all the things we had done that day. It was beautiful to observe Christian having a signed conversation with someone I know he cared about. I know this was a very special time for Christian, as well as a strong memory that I will never forget.”

I began to look at Christian’s future beyond school with a new outlook. It was inevitable that this time he would graduate. It was extremely important to us to make his transition as smooth as possible. His life was full of meaningful activities, and we wanted this to continue for him.

Christian’s love of chocolate found him a job. Ann had discovered early on that Christian loved chocolate. Their discovery came on Christian’s first trip to the vending machine. He had no idea at the time that “the big box” could spit out this delicious chocolate... at least he didn’t on the first trip. The next time, he knew what was coming. He quickly learned the sign for chocolate. Ann taught Christian that he could put money in the machine and get chocolate. As time went by, we expanded that theory. We bought Christian a small vending machine. We had permission to put it in the classroom. Christian learned to load it with chocolate, and other treats. He traveled to Sam’s Club to buy supplies for his vending machine. He learned to collect the money out of the machine. After graduation in 2004, we had special permission to keep the vending machine at school in the classroom. Christian went to school once a week to load the machine. He was able to visit with his old schoolmates and teachers while he was there. We were working on getting him another vending machine to be placed somewhere else in the community.

NOTES AND COMMENTS FROM MELANIE

The obstacles that we had to overcome for our son Christian were worth each struggle...each tear...and every frustration.

Christian did graduate in May of 2004. He was given an award for “Vocational Achievement”. He deserved it.

We seriously started transitioning Christian into his “life beyond school” in October of 2003. We held “transition parties” for him. (call it a party....and they will come). We dreamed of what the perfect life would be for him....and we worked toward those goals.

In August of 2004, Rodney Richardson came to work with Christian. Rodney had no experience or training to work with the deafblind. I called him our “intervener in training”. Rodney worked very hard to learn signs and the calendar box to communicate with Christian. He and Christian became buddies, and I think if you asked Rodney, he would tell you that... Christian was the teacher, and he ...the student. One of the dreams we had for Christian was that he would have a car and a driver to take him to all the places he liked to go. Gary and I bought that car for Christian, and Rodney drove Christian all over our community.

In February of 2005, Gary, Landon, and I presented at the TSBVI biannual statewide conference in Austin, Texas. Our topic was “*Christian Knapp, The Great Motivator*”

Ann and I had also presented “*Christian’s Exceptional Day*” at the TSBVI biannual conference in 2003.

I am convinced that Christian excelled because he had an Intervener. I also believe that Christian needed an Intervener that had training and experience.

I know my son was living his life to the fullest and was happy those last few years of his life. This gives me some peace.

My vision is to see that each child that needs an Intervener has one. Intervention with a deafblind child as early as possible is crucial. I also believe that Interveners need to be recognized as professionals. This is a highly specialized job teaching someone who is deafblind. I believe that the intervener should have the education and background to help her/him as much as possible.