Keynote Address by Lou Ann Walker at the Second National CODA Conference Reflections: Codas and Cultures Co-Sponsored by CODA – Children of Deaf Adults and the National Technical Institute for the Deaf at Rochester Institute of Technology Rochester, New York, USA, August 21-23, 1987

About Lou Ann Walker

A native of Indiana, Lou Ann Walker studied comparative literature at Harvard University. She also holds a graduate degree in French Language and Literature from L'Universite de Besancon in Besancon, France. After college, she worked as a reporter at The Indianapolis News, and then moved to New York City where she worked on staff at several magazines, including New York, Esquire, and Cosmopolitan. In 1983, she was awarded a Rockefeller Foundation Humanities Grant to do research on hearing children of deaf parents. That research led to the writing of her memoir, A Loss for Words. An article she wrote on deaf street gangs for People Magazine (July, 1982) was nominated for a National Magazine Award. She frequently writes for such publications as The New York Times Magazine, Parade, American Health, Life, Ladies' Home Journal, The New York Times Book Review, and the daily New York Times. Her non-fiction children's book, Amy, based on a Supreme Court case, was named one of the ten best children's books of 1985 by the National Children's Book Council. A Loss for Words won the Christopher Award for humanitarian writing in 1987. She wrote the introduction to a new edition of Helen Keller's The Story of My Life that was published 1988 by New American Library. Lou Ann lives in New York City and Sag Harbor, New York.

## Keynote Address

Last night as I walked into the dining hall where all of us were meeting, a feeling of elation and exhilaration came over me as I realized that we all shared something so extraordinarily important. Two or three years ago I couldn't have imagined being in a room with that many people who were expressing the kinds of things I'd felt, who were telling the same kinds of funny stories I'd gone through and who understood what I was thinking and

feeling while I was growing up. I felt these things were all secret. When I was a child, the voice within my head was not even telling me the things I was seeing or doing. There was a natural inhibition. I wasn't allowed to think about those kinds of things or contemplate them because somehow a special pact had been formed with my parents, and with deafness itself. To be in that room watching everyone talking to everyone else, seeing what was happening and understanding it, was just extraordinary. I felt this was the voice I wouldn't let myself hear when I was a child, that I wouldn't let myself understand when I was a teenager.

Last night some people were sharing their childhood thoughts that their parents actually could hear and were only pretending to be deaf. I thought that my parents were spies and wrote about that in the book. I realize, now, how funny it is but when I was a little kid it wasn't funny. I really thought about it and devised elaborate schemes to prove they could hear. When my mom and dad read that section of the book, they didn't get it. They thought it was very bizarre. Only later, when they began talking to other parents who had hearing children – and those children were admitting the same thing to their parents – did they finally understand what I meant. Of course they were perplexed, but at least they and I realized – independently – that although there were tremendous differences between us and other families, we were also in many ways the same.

Since the book has come out, a number of things have happened. I see my parents more clearly, I think. I understand them maybe a little better. I understand myself a great deal better. And I've looked at situations far more clearly.

The moment I felt I had to write A Loss for Words occurred when I was about 25 years old. It was at Christmas and I'd gone home to visit my parents in Indiana. My family then drove to my grandparents' house in Greencastle, Indiana. It was a wonderful Christmas, filled with fudge and all the treats we could stuff down ourselves. My grandfather, who was a very taciturn man, said, "Let's go for a ride." He wanted to learn sign language. This was the first time in his life he'd ever even talked about sign language. (Of course I'd been functioning as the interpreter all day long.) We went out for a ride: "right" and "left" he learned. We turned right and left all over Greencastle, into every alley and every dead-end street. My mother and I were sitting in the back seat, my sister Kay was driving, and as we rode, my mother said, "That's the house where I was born…See that tree? We used to have a tree house there and I played tea party with a little girl...I wonder what happened to her?" All these sweet things were happening in the back seat. When we got home, my grandfather walked in the door and told my grandmother very proudly: "I learned some signs today." Well, of course he'd forgotten them right away, but he'd tried.

Later in the day, after more goodies, we were packing up to leave. My father was stowing the presents in the trunk of the car, when my grandfather turned to my mother and started to speak to her in the kitchen. I went up to sign and he shooed me away, saying, "No, no, I want to tell Doris Jean this myself." Then he took my mother's hand and he learned over toward her and used the stage whisper he had for talking to her, and said: "I want to tell you how special you are to me and how proud I am that you're my daughter and how much I love you." My heart was filled with joy. I thought it was wonderful that he could finally say that to her. We got out into the car and drove along and my mother turned to me and said: "What did he say?" It was that moment of miscommunicating that hurt so much. As a writer I cared about communicating. As an interpreter, I was the communicator. And here was a poignant moment just lost. It broke my heart. At that moment I realized that I had to tell my grandfather what my mother was really about. I wanted him to know what had happened to me when I was put in that position. I had to tell him what I had watched. The book was hard to write because I kept thinking of my grandfather. He'd lived with my mother all of his life and yet he'd missed so much of her essence. He died before the book was finished. So much had been lost.

I remember going home and being with my grandmother the night before my grandfather's funeral. We were sitting in her air-conditioned living room on a sticky August night. She had a book of signs open on her lap. She'd always done a kind of pidgin sign language where she leans forward and purses her lips, saying some words, drawing a few letters on her hand, then throwing in a few signs and nodding her head. Mostly she wrinkles up her forehead as if that will make you understand. Oddly enough, my mother never said anything to me about how she felt toward their way of communicating. This time in the living room, my grandmother held the book down with her elbow and was signing to herself: "This is 'apple" she said, "and I know this one." I asked her why she never signed these words to Mom and Dad and she said, "Oh, they go so fast. They wouldn't wait for me." And I said, "But the point is that you can do more than you do. Why don't you try it?" "No, I can't."

Well, the next day was my grandfather's funeral and it was very hard. You know what it is like to interpret something so sad. A funeral is awful when you're the grandchild. After my grandfather was buried, we went back to my grandmother's house where she said something that broke my heart all over again. Sitting in the backyard, she was saying: "Well, you know, I've had some terrible things happen to me in my life. Doris being deaf was the first one. Grandpa dying so suddenly..." and then she went on to list the others. I was standing there interpreting for my mother that her being deaf was the worst thing in her own mother's life, and I was crushed.

Later that day something else happened to further hurt my mother. She had bought a TTY for her own mother and had brought it to her this day. They live about an hour's drive from each other, and my mother, handing it over said, "Here. Take this. We want you to be able to call us if you want us to come help you with something, or if you just want to chat." And my grandmother said flatly: "No. I can't figure this thing out. No, no, don't leave it." My mother told her to put it on a table for the time being. "You don't even have to use it for a while. You'll get used to it. I'll show you how." "No, I don't want it," my grandmother answered. Now this is the grandmother who had said to me: "Be good. Your parents are deaf. You have to be good. You have to take responsibility for them." And this is the grandmother who wouldn't even accept the TTY. As Codas, these are poignant moments we face all the time. Some of them are excruciating. That's why the voice in my head was never turned on. I just didn't want to be overwhelmed by sadness.

A few of the things that have happened since the book came out have been extremely positive. My father says, and I think this is true, that he gets a little more respect at work. A few of the other things that have happened have surprised me. For example, my Uncle Garnel (who is also deaf) became very ill soon after Aunt Imogene died. Naturally, my father's hearing brother didn't want anything to do with putting him in a nursing home, nor did he offer any other solutions, so the entire thing was left up to my father. Unfortunately, Uncle Garnel had burned his bridges with my mother and she wasn't about to have him come live with us. In the past, she would pick out his Christmas present – say a shirt – and then he would thank my father. Never my mother. When there were no other solutions left, my father chose a nursing home that was near our house so he could visit frequently. When their older brother, a hearing man, went to visit him – he went only once – Uncle Garnel was sleeping. He didn't even bother to wake

him up. At any rate, my father did something that was very curious for him. They had misspelled Garnel's name – it wasn't an easy one. My father went to the office and insisted that the name be changed immediately on the door and by his bed. "This must be changed," my father said. "He sees this all the time." After some resistance, they did. I realize this was a big step for my father. He was taking charge. And it was a lesson to me. We were continuing the process of separating. I had to remember – and be reminded – that my parents were and are independent and perfectly capable of taking charge.

Before that day, I remember having gone home wondering how they would write a business letter or how they would get certain things accomplished. I would fret and fret over these kinds of details. My worrying didn't do them any good. It made our time together fraught with an agony that didn't have to be there. I was writing the book at the tail end of my twenties, and the beginning of my thirties. The twenties is a time of turmoil anyway – that's documented in Passages. But for me it was a kind of delayed adolescent rebellion. I was just getting mad. I was sick and tired of seeing some of the things I had seen while growing up. Suddenly I found myself breaking things, and I was furious and cursing. And yet the anger was a strange, amorphous thing until I began with the story of my grandfather. Systematically, I began going through the things that had happened to me as a child, what I'd seen, what I'd experienced, and I started putting those things down on paper. At first, I just wrote. Then I would shuffle the pages and juxtapose different scenes with each other, and suddenly I would say, "Oh, that's it. They basically ripped my father off." Or, "I can't believe so and so did this." It's very hard to look at the rest of your family and think there are ways that they could have behaved better.

What I'm trying to do now is set things up so that they do happen in a better way. I don't interpret as quickly for my grandmother because I'm trying to get her to sign for herself. I'll pick up if she doesn't do it. I'll even say, "Why don't you sign that to Mom yourself? You can tell her."

In this growing sense of independence my family has, I was amazed to learn that my father was leading a march in downtown Indianapolis. You have to understand that my father is very shy. My sister was standing in her office looking down when suddenly she saw my father in front. It was a proresidential school protest. My father is against the concept of Least Restrictive Environments – LREs. Her own father – my sister couldn't believe it. "My Dad's Abby Hoffman!" she laughed to me over the phone. And we were all thrilled.

But everything isn't roses. My father has been working for years for organizations for the deaf. He was so proud when he was appointed to the Governor's Council, an advisory group for the State School for the Deaf. My father is the only deaf member of that committee. He was to advise on vocational programs. He sent me a copy of the governor's letter – he'd framed the original – he never does things like that. I was so proud of him. But when I went home to visit last week, I found that there was a group of teachers at the school saying that because my father didn't go to college, he shouldn't be on the advisory panel. I know what that's about. I know they were jealous. My father said he just couldn't stand having them talk about him that way. "I think I'm going to resign," he told me. I told him: "You can't resign. You are the only deaf person on the panel. There is nobody who knows anything about deafness on that advisory committee. You have to stick it out. You are advising on the vocational department." I feel sure he's going to resign anyway because of the pressure he's getting from people who want the position. And that leads me to one of the other topics I wanted to discuss today.

There is a lot of mea culpa in being a child of deaf parents and you must understand that what I wrote were my personal experiences – things that had happened to me and that I'd seen. I didn't speak for anyone else and I don't care to speak for anyone else. There are people who become very strangely defensive about this intensely private area of their lives. The book is about what it was like for me and I get goose bumps when I hear similar experiences other people have had. But I don't pretend that my experiences are anyone else's. One of the things I've seen too much of is guilt. There have been studies done of survivors of Hiroshima and the Holocaust, and for them there is something called "survivor's guilt." "Why me?" I don't think that the guild I feel is in any way proportionate to that, but there was a guilt that was hanging over my head that sometimes came from very wellmeaning people who would say: "Oh, both your parents are deaf, and you three girls can hear. Isn't that wonderful that you're normal?" Now sometimes you wish people wouldn't say anything. That they would just register it and not make any comment. To hear that kind of thing again and again is aggravating, and sometimes leads you to say: "Well, why me?" There are times when you puzzle about that kind of thing. There is plenty of normal, everyday, run-of-the-mill guilt to go around. I know part of my

anger that bubbled up when I was in my late twenties will never go away completely. There are times when it just surges up within me. At those moments, I very quickly have to start putting things into perspective and reorganize my thinking, because the alternative is too terrible.

There have been some very fascinating studies done of children who have alcoholic parents. Please understand I become very angry when people consider having deaf parents to be a pathological condition – which a few have tried to do. I don't feel that way at all. It is a condition that is very curious and unique and important for us to consider. As children we were never allowed to think about it. We must now face it, think through it, figure out how we can change ourselves for the better if we feel we need or want to. The work with children of alcoholic parents is fascinating because these children take on coping roles that are very similar to ones I've seen and heard about from other Codas.

There are essentially four major coping roles that a child takes on in a situation where there is a great deal of responsibility. First, there is the family hero, who does everything and takes that responsibility – and goes crazy doing everything. Then there's the scapegoat, the child who gets blamed for everything. Another is the quiet on or the lost child. That's the one who is alone and angry and feels misunderstood. That child basically checks out of the family, doesn't sign, and doesn't deal with anything going on. They don't pick up their hands in order to be with the rest of the family. The fourth is the mascot, the sort of family ham or the jester who gets a lot of attention and is relieving the tension in the only way that child can. But what happens in those childhood coping roles is that they're such comfortable roles that we fall into traps and don't know how to get out of them when we're older. That's the dangerous part, when you fall back on something and then find yourself messing up other things. You have to step back and see how you can change, how you can alter your life so that you are leading a life that is useful to you.

It's pretty obvious that the <u>family hero</u> has to learn to relax and let go and stop being responsible for everything. I was married last year and even now my husband has to say "chill out" when I'm starting to get the wheels turning and I'm in my "go" mode – otherwise known as my "interpreter" mode. And I can see it in myself. I have a sister who is something of a <u>lost</u> <u>child</u>, and misunderstood because she doesn't usually sign when my parents are around. That breaks my heart. That's the one that needs to express the anger that's built in. There is a kind of hopelessness in that sort of person who has to get out of herself. We all must feel there is hope in our lives. The <u>mascot</u> needs to learn to take himself or herself more seriously and find ways to use all that pent-up energy. The <u>scapegoat</u> has to come to terms with his or her own problems. They aren't the problems of the parents. We are individuals.

There was an interesting personality study done in Minnesota. They studied traits that were and were not inherited. It's just fascinating. For example, the feeling of well being, of just being happy, is an inherited trait for many people. The ability to feel social closeness – about a third of all people have that as an inherited trait. The ability to become enraptured by beauty, either listening to a concert or looking at a painting and really feeling how wonderful that aesthetic experience is – all of these qualities are inherited. Nobody knows, of course, what qualities are or are not inherited in a child of deaf parents. There are times when we need to figure out what happens because we have deaf parents. And then we need to understand how we've become the way we are for reasons that have nothing to do with the fact that our parents are deaf.

I have been trying to figure out what is the same and what is different. There are a lot of things we have to take in hand. I know that my cousin who has a quadriplegic mother sometimes confides in me that she is exhausted and sometimes angry about running errands for her mother. Particularly when people expect her to do things and don't appreciate her. In another very interesting study I've read recently, there is a psychological theory that people recreate their lives in their own memories to suit their present images. A few times I've had call-ins on radio or television talk shows. Sometimes someone will say, "Well, I had deaf parents and nothing was different for me." That may represent a certain kind of defensiveness, or it may just bear out what they're saying at Duke University. That we alter what happened before in order to suit ourselves now.

Being Codas we are in a very delicate position, one that occasionally makes me a little nervous. For example, when I was in Indiana, my father said to me that there exists a group of people in California who are saying that because they had deaf parents they were abused as children when they had to make so many phone calls. I know what that's about. That's sort of deaf scuttlebutt getting a couple of innocent things twisted around. At least I think that's what it is. Jim Stangarone, last night, was talking about the fact that Codas should be a positive force for change and I think he's absolutely right. He was talking about the fact that Codas are the one group who has lived between the hearing and deaf worlds and we really know these two worlds intimately. Some use should be made of our knowledge – by educators, by all sorts of professionals working with deaf people – and by deaf people themselves. We've got to use the knowledge we have of deafness carefully in order to build bridges between hearing and deaf people. These bridges need to be built.

Now some of what I've said seems sad, but many of the most important parts of my book were the happy parts, the joyous parts, the parts where I figured out it was just a book about families. And sometimes I took for granted the joy that was in my family. But setting it down, I began to respect it. I began to cherish it.

There is a very curious quotation from Lord Byron who wrote: "One lies more to oneself than to anyone else." A Loss for Words was, for me, a process of truth-telling, of figuring out what it had really meant being able to hear the kinds of things within myself that nobody else had ever been able to say to me. At the end of the book, there's a little scene at my sister's wedding with my parents dancing. It was such a magical moment, watching my Mom and Dad twirl around the dance floor. When I got married last year, we ran off to Europe and sent a telegram home. Later I learned that my father had shed a tear realizing he wouldn't be able to walk me down the aisle – my mother told me that. So we had a big wedding celebration and my father walked me down a beautiful, manicured lawn in Connecticut where the wedding party was held. But what was so wonderful about that moment was thinking how far I'd come, how far my parents had come, how I was finally growing up. Everyone at the party – many of whom had never met a deaf person before – were excited about meeting and really getting to know my parents. It felt as if we'd all gotten a special gift. I was able to enjoy them as Mom and Dad and I was able to figure out how much I'd learned from them, and how much more there was to learn. It's wonderful coming to terms with yourself.

Thanks you very much.