

## "MIKE PRICE: A DEAF-BLIND PERSON'S PROFILE"

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Carol Yoken

Mike Price is in his early twenties. He is tall, broad shouldered, and very handsome. He lives in a suburb of a large city and walks to his job as an assembler for an electronics firm. Although Mike is diagnosed as having Usher's Syndrome, his hearing loss is not so profound as to prevent him from hearing and understanding speech, provided he is in a quiet environment, using his hearing aids, and those with him are talking somewhat louder than what is usual in conversation. Mike speaks, but he has to remind himself not to mumble, and he has some difficulty pronouncing the words that he does not hear clearly.

His vision is impaired by the night blindness and tunnel vision of *retinitis pigmentosa*, and by inoperable cataracts in both eyes. Within the past year, he has become totally blind in his right eye, and he has a field restriction and only blurry perception in the left. In a good lighting situation, with careful positioning of the person communicating with him, Mike can combine what he hears, lipreads, and, for those who use sign language, what he reads on their hands, to be included in the conversation. At other times though, when he is in a dimly-lit restaurant where there is a background hum of noise, for example, he is virtually totally deaf and blind, and can receive communication only through the tactile method of signing that he is beginning to practice.

Mike is not willing to have information about his current life published, for some of his relationships, particularly those with older women, are complex, and he feels that out-

siders are not likely to understand him. He agreed, however, to share his experiences from the time he was in school—both the 10 or 12 years he spent at a state residential school for the deaf and his 2 years of college at Gallaudet. His account of the treatment he received from other people and its influence on his development may, of course, be biased by his own perceptions and memory. At the same time, many of the very positive attitudes he now expresses appear to be solutions that he recognizes intellectually, but does not always incorporate into his behavior. Nonetheless, his story seems important, for Mike explains in detail what most other people with Usher's Syndrome often allude to—teasing and rejection from other students, lack of understanding from school personnel, and an early preference to be alone.

"I had lots of problems in school and with my family. First, when I started, I went to a hearing school for the first and second grades. I don't remember the name of the school and stuff like that, but I know I didn't do well at all. The teacher knew that I wasn't able to learn or keep up with things in the classroom, and I didn't get along with the other kids; we couldn't communicate. So I left that school, but my parents didn't know what to do. They didn't think of sending me to a deaf school because they didn't know anything about it. (Mike's family lived on a farm at that time; one of his three older sisters also has a hearing impairment, but she was able to continue in public schools.) Well, I wasted some of my

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Ms. Yoken is with the National Academy of Gallaudet College.

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time then because I just stayed home and worked on the farm when I was about 7 or 8 years old. I don't remember when I started at the school for the deaf and blind. I was at least 8 or 9 years old, no less than that." Mike's school, like several others in the country, was established for both blind and deaf students; their classrooms, dormitories, and activities, however, are separated, and the two groups rarely have any contact.

"I guess from the beginning I was having vision problems. The most I knew, I couldn't see in the dark. I was always getting behind other people when we were going places. I got behind, and I was the last person to come along until I could find my way. I began to be really frustrated with that, and I thought I was the only one in the world. I didn't know anybody else who had similar problems, except for the blind people in the other department, and we weren't living together. But sometimes I'd look at them and wonder if I'm like them or not.

"I noticed that I bumped into people from sideways. Sometimes I thought they were bumping into me and didn't realize that I was the one that just didn't see them. Or they'd wave at me and say I'm always stuck up. I just couldn't get over that. When they started calling me names like that, I began to move my head and look around to catch what was happening, and they'd call me more names and say, 'You're suspicious, suspicious.' It wasn't true. I was just trying to help myself.

"I used to play ball, and at first I thought I was better than a lot of my friends, but I began to realize when they started talking about me, or the coach started complaining, I began to realize that I made a lot of mistakes. I'd bump into people. I didn't see everything at one time, or I'd miss a few things, like a ball passed me and I didn't know it was coming my way. Whenever I could see the ball at the right time or in the right place, I did well. When I couldn't, I did kind of sloppy or bad to other people.

"I got frustrated, and when I was a little older, I was beginning to have a hard time with the other kids, because I guess we didn't accept each other. I didn't understand them and they

didn't understand me. I'd complain to people a lot, but they didn't understand; or they didn't want to listen; or they didn't think it was important. And I didn't know what to tell them. I couldn't see, but I didn't know what I couldn't see, and with r.p., your eyes don't look blind. I think there were a lot of misunderstandings—they and me.

"The more problems I had, the harder it was to solve them. I didn't have many friends. When I got into junior high and high school, I got to where I didn't want to go to the parties or go places in the dark. I just didn't do a lot of things that most kids do because I remembered the things when I was growing up, and everything I'd do, I'd get frustrated or down or depressed. I didn't think it was worth it to try to do things because I just didn't know how to deal with them or how to enjoy them, unless I was with some friends who knew me, and I could be comfortable. That would be maybe the only time I'd do things. I just usually stayed in my room all the time.

"When I was in my freshman year of high school, I think I was beginning to be more mature, but by then it didn't seem to help because it was harder for other people to understand me. You know, I'm talking about gym and football . . . anytime I'd do something wrong, or bump into people, they'd think about that and remind themselves about things that happened before. People made fun of me. Instead of my name sign with an *M* on my shoulder for Mike, they made it with the sign for *blind*, and they tapped everybody on the shoulder with *blind, blind*. Kids can be cruel. I called them my friends, but they could have been my worst enemies.

"Or else people would overlook me, just not pay attention to me. It may have been normal for them because they really didn't understand me at all. Nobody really understood what the problem was. I didn't either. I just felt I was left in the hole and nothing could be right. I had to rough it out, and I didn't know how. Maybe because I wasn't smart enough, or I just didn't have the information that could tell me what was wrong.

"One time in a basketball game it was the most embarrassing time, I think, in my whole

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life, especially because of the coaches. We had a tournament. We were in the second position, and it was the last game. We couldn't finish it because there was a bad storm and a blackout. I had only one friend, and I knew where he was before the lights went out. He wasn't too far, so I ran to look for him to hold his elbow, and I told him what was wrong. I couldn't see in the dark. So he helped me and we went to this waiting room. When the lights went back on, everybody started laughing at me, even the coaches—I had two of them, and they just laughed. 'Oh, did you see Mike . . . he was looking, looking, he couldn't find his way, he finally grabbed hold of Don.' I was just standing there. I couldn't even stand up for myself. Everybody was just laughing. I really hurt a lot. It was hell for me, suffering like that. And things just didn't seem to get better.

"I went to counselors, but the people I talked to didn't ask me questions like, 'What's wrong with your vision?' All they asked was why I had so many emotional problems. I tried to tell them why but . . . I kept trying to tell the teachers in my own words, in my own vocabulary, what was wrong, *why* I had so many problems, but nobody could understand. There were some teachers there that I really liked, I really admired, and I think that there was one teacher who believed that I just couldn't see well and she did what she could. But all the other teachers in the school thought I just had a bad attitude. I don't think I had a bad attitude; I just didn't know how to tell people what was the matter.

"A lot of times in class, people would tease me and the teacher would say, 'Why don't you get up close to the board?' but that wouldn't help. I just was never comfortable. My teachers said, 'Wear glasses.' It didn't matter if I wore glasses. I told them the doctor said this is all they could do for me; the glasses I had were as strong as they could make. It didn't matter how thick the glasses were. If they were any thicker, I wouldn't have seen at all; it would have been all blurred. I had people tease me because my glasses were way out like that.

"I don't know how I learned in class. I got through, but what they did with me, they just

kind of kept me. They didn't really put me where I should have belonged, and I wasn't getting anywhere. They let me miss a lot of things and just go on. There were times when I couldn't—like math—I could do some of the harder math, but I couldn't do some of the basics. I really couldn't see the board at all. Using what I heard was the best learning method for me. And of course reading, what I could read.

"Most of the teachers talked and signed, so I could hear some of them. But there were several deaf teachers who just signed and the students just signed. I had a hell of a time. I didn't get good grades. They always put me in the lowest class, but I was just as smart as anybody else . . . if I'd had a chance to learn. Maybe part of it was I didn't want to, but I don't think so. I think that I was so frustrated that I became less enthusiastic. And so you just sit there in class and daydream. I know I'm not dumb. Whatever I learned, I could understand well. But that was about the only information I could collect unless I wanted to go home and study. Really, if I couldn't hear, I would have missed everything. I think people would have thought I was retarded or crazy and sent me to the mental hospital.

"I took a driving course in my junior year. I *knew* right there that I didn't want to drive because the teacher said I was always going off the lane. I couldn't park right. In front of the building where he wanted me to park, I would always come too close and hit the building, and he'd get mad. I think they thought I had a bad attitude or I was angry with them. It wasn't that; I'd just get so frustrated. I didn't know how to deal with it. The teacher even grabbed hold of my shirt, and then I really got angry, 'cause that scared me. I didn't know how to tell them that I just couldn't do it. They asked me, 'Why? why? why?' and they'd always think that I was 'a quitter, a quitter.' But I just thought it's better if you quit, 'cause if I stuck in there, everybody would get me angry and I'd start fighting.

"I think my junior year was my most unhappy year. Some girls who I wanted to be with never wanted to be with me, and I don't know, I just got really frustrated and unhappy.

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I was anxious to finish school. I was just tired of being there.

"When I finished high school, I was accepted at Gallaudet. People talked me into going. They said, 'No matter what the problem is, go anyway.' Not only that, I didn't have anything else to do, and I couldn't get along with my dad. When I was in school, I used to go home on the weekend. I would rather be home than at school. At school, I didn't have anything I could do. Home I could take walks or go bike riding unless the weather was bad and I couldn't go out.

"But my family is the kind that never smiles. My father was always angry and complained about everything. He just always did things the hard way. I think that's where I got some of my attitudes, too, being negative. My family is like that. But I'm trying to change now. My dad was really rough on me. He would shove me, push me around. He would never sit down and talk with me, never. Things got pretty bad. My deaf sister and I would talk about the problems around the house and why. She and I signed; we were the only ones who could really communicate. Everybody in my family is much older than me. My father's old enough to be my grandfather, and my sisters were all dating and getting married when I was young, so I really never knew them. I was closest to my mother.

"I went to Gallaudet in 1974, but I don't think I was really prepared to go, because even though I passed my courses, I had some weaknesses, and I knew I would have a hard time there because I didn't have a good high school education. And I think I was scared, too, because I didn't know what to do. I still didn't understand what was wrong with me. I just thought I was the only one in the world. And I hated to go because of other kids I knew in high school who were there. I didn't want to see my old classmates because of the way they treated me in high school. Even when I got to Gallaudet, they wouldn't speak to me, and they'd tell other people, 'Oh, that guy isn't important, don't pay any attention to him.'

"And it was more trouble because my family didn't support me. I told them I couldn't see, but the only one who ever really took it

seriously was my mother. That's just the character of my family. We don't believe things, or don't accept what other people say. They didn't want me to go to college anyway. If I ever complete it, I'll be the first child, and there's only two in our relatives who did.

"My first year at Gallaudet was hard. I had some friends, mostly multiply-handicapped students—one guy in a wheelchair I played chess with. There were some girls I was friends with, and I could go to their rooms and talk. But I had a lot of problems, and I was really angry and emotional and got into fights.

"The summer in between my two years of college, I had trouble with my family. Things had just built up on me for so many years. I knew every time that I wanted to know what happened or wanted to ask, 'What happened over there?' other people wouldn't tell me. They could see and hear and knew exactly what happened, and I would just be standing there and have no idea.

"What happened that summer, we were playing horseshoes—me, my dad, my brother-in-law, and one of the neighbors, Gary. Gary's son was outside playing. He knocked down another boy. Well, the boy's father came out of his house and knocked down Gary's son; because Gary's son knocked his son down. Gary ran over. I didn't know; I was just playing horseshoes. I didn't see him leave, and I didn't know he was gone 'til I looked up and saw he was missing.

"Pretty soon, I saw my dad looking over that way, and my brother-in-law looking over that way, and I looked that way, but there were cars down the street and it was hard for me to see the depth or tell what was happening. I didn't know there were kids out there 'til later.

"So I was getting really anxious to know what was happening, but I thought, well, if I ask, they won't tell me; that's the way they are. They just don't understand. I think sometimes they think that I'm dumb and it's just not worth it. I'm not dumb. If I were dumb, I wouldn't be curious and asking what's happening. I feel like I need to know what's happening to satisfy myself.

"My dad and brother-in-law were together

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and talking. I think sometimes I'm jealous because my brother-in-law and my dad can communicate and they do a lot of things together. More than they do with me. I think that hurt me some ways. But they were talking and talking, and I'm sure they were talking about what was happening and they knew what it was. So I came up to my brother-in-law and said, 'What's happening over there?' And he said, 'Oh, nothing.'

"I got very pissed off. I said, 'You're my brother-in-law and you just treat me like a slave or something.' I was mad. I didn't get an answer to what was happening, and here they understood it. They left me out. I picked up a rock and threw it down, just to get it out of my system. I wasn't throwing it at them. My brother-in-law didn't realize that. I threw it down and it bounced up. I think it hit him. I think that's what happened. But he gave me a shove. Right there, I just exploded. That's where the fight started. He was wrestling me, my dad was wrestling me. They were fighting me—but that wasn't solving the problem. I think they were trying to calm me down, but that wasn't going to do it. Gary came over and there were three against me.

"Boy, I was getting stronger and tougher, and I got hold of my dad's arm and I swung him. He was kind of flying in the air, real low above the cement on the driveway. He finally hit his head; his hat came off and he hit the ground. I was still angry, and I said, 'Keep your hands off me and leave me alone.' I told them when I'm angry like that, I don't want to be bothered, but they were still bothering me and yelling at me. I didn't see him, but Gary got behind me and was trying to pin my arms back. That made me a little more mad. It was hard for me, but I finally got him off. They gave up and didn't touch me anymore, but I wanted to show them that I *didn't want* them to touch me.

"We went into the house and I picked up a knife, a steak knife, and I had it in my hand. I was just trying to scare people. I wasn't going to attack them or anything. But my dad, he was gonna call the sheriff. I said, 'Just go ahead.' Then my brother-in-law said, 'No, No, forget it.' So I finally left and walked about a

mile to a girl that I knew. I went to see her and talked it over with her. After that, I had several more fights with my dad, and I even broke his glasses. He had cuts on his eyebrows. He tried to fight me back, but he couldn't.

"It was really an emotional experience. But I knew what I was doing. I wanted to get it out of my system and show people I was serious. But they thought I was crazy. They wanted to lock me up in the state hospital. I've just had a lot of emotional . . . especially when it's built up over so many years. I just didn't know any other way. I would have liked to have done it a nicer way, but I just didn't know how."

Mike went back to Gallaudet for a second year, and that is when he learned that he had Usher's Syndrome. "I started going to the infirmary. Back in high school I started that, just going sometimes and talking with the nurses. I did it again at Gallaudet, and finally I told one nurse about my high school life and how frustrated I was in the dark and things like that. She suspected that maybe I had r.p., because she knew Art Roehrig who worked at Gallaudet and had it. She thought maybe I had the same problem, so she volunteered to take me to the National Institutes of Health in Maryland. I spent 8 hours there with her as my interpreter. That's when I found out.

"I was really shocked. I couldn't believe it. I told the doctor, 'All this time and I didn't know. That was why I was so frustrated and unhappy.' After all those years. I don't know what it would have been like before if I'd known the problem better. I might have been the same, I don't know. But I was glad to find out. But it was also hard for me to believe the other stuff.

"First the doctor wanted to know if I wanted to see a counselor. He was a little bit worried; so was the nurse. But then he said okay, he would sit down and show me what was the matter. He had some demonstrating pictures and he showed me those and did some drawings of how much I could see, degrees, and stuff like that. I got the idea, but I just couldn't believe it—that was it. And he told me, maybe in 5 or 10 years from then I might become totally blind or something like that. He said, 'Your vision *will* get worse; there's no

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question about that.' He also told me about marriage and to be careful about what girl I marry. He said that I might give birth to a child with the same condition. And he explained about the dark and about my limitations. He told me a lot of things; I don't remember them all.

"Then it took me some time to realize how serious it was. I still have problems accepting it, but I think I had more problems at first because I didn't know *how* to accept it, until I learned there are a lot more people who have it. Now I can look at them and see how well they do. But it took me a long time. I think I was close-minded, and it took me a long time to become more openminded about it.

"I stayed at Gallaudet but I stopped going to classes. I guess I really didn't want to learn. I think I was pissed off. I didn't know what to do, whether to leave school or stay. Learning was really hard for me. I could understand if I wanted to, but I had to study hard to understand. I was having a lot of personal problems. I talked with my friends. One person would tell me to do one thing and another would tell me another thing. They wanted me to do this or that, and I didn't know who to follow. About my future—what should I do? What kind of teacher should I be? should I work now? or stay in school? They were mostly staff in the dormitory, some teachers and nurses. They all looked at me different and I didn't know who to follow or who could understand. It was like I was just left out in the ocean and didn't know what to do. I didn't want to go to counselors. I get tired of counselors. They do their job, but somehow, I'm just tired of it. I just rather be friends with people.

"I went back home and I was wishing I didn't. I had a lot of problems. Bad fights and arguments with my dad and brother-in-law. I wanted to be alone. I wanted to do what I wanted to do. They wanted me to go to work right off. They weren't able to help me or to understand. I just got there and boy, they were right on my back, pushing me. I was really depressed. Part of it was, before I came home, my mother was in the hospital for a week and they didn't let me know. They knew I was close to my mother and I would have wanted to

come home. She had already died when I got there; the day I got there, she was already dead. That tore me up. I don't know what it was with my family. Communication or something. I think they didn't really like me. I think it's because of my attitudes. I really can't say how I acted, 'cause I can't see myself. I just know that's some of the reason."

Mike stayed with his father for a few months, trying to find a job through vocational rehabilitation. His rehabilitation counselor suggested that he go to the larger city that he lives near now to receive a full evaluation of his skills and needs for training. He moved, and has been living in that area for about 2 years. He has thought a lot about what would have helped him as a child and teenager to understand himself better. He feels that the two most crucial aids would have been accurate information about his limited vision and the support of his family.

Mike says, "I *wish* when I was growing up that somebody had come up to me and had a movie camera and didn't even let me know or see him taking pictures, for a whole day, everywhere, a lot of places with different people, then showed me the things that I missed and why I didn't see them. I think they should take movies of some of these students now and show the people who are normal—teachers and professionals—to help the students.

"He may have to have note takers and maybe the teachers are going to have to work a little bit harder. They need to find out if the student can see the boards, then change them or make extra copies of things for the student. The teachers get good pay; it's not gonna hurt for them to work a little bit more. I think they have to learn to be more patient. Then they can teach the student to take more responsibility for himself.

"But I think the family is the most important thing for the child. I think that my parents knew that I had r.p., but they never told me what the doctor said. I can't prove it, but I think so. The family has to work with the child when he's young. When he's depressed, they need to explain, 'Mike, I know you like basketball, but you know, when you're older, life's gonna be different for you. Now you may

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want to play basketball and be on the first string, but, you know, when you get older, it may not work out that way because of your limitation. But later you may want different things.'

"If I had a child with Usher's Syndrome, I would send him to a doctor more frequently than normal children to see if there's any change. That way you can kind of prepare for his future. I would do all kinds of things, play ball, play all kinds of sports that I could think of and see what he enjoys the most, and work with him, like a coach, even though when he's older, he may not be able to do a lot of those things. As he got older, I would explain it to him. I would always have my wife or me keep in touch with the teachers or the principal and find out how he's doing. If he's having problems, emotional problems, then we'd go to a counselor with him. I would go too, because there are some things I may not understand. I know all Usher's Syndrome is not the same. But if you work with kids when they're younger, then when they're older, they have a good chance to be a better person."

Mike still doesn't like to go to counselors, and he feels that they would be more useful to him if they came and watched his behavior in order to tell him, from an observer's point of view, what he is doing well or poorly. He does not associate much with deaf people and says that he is "pretty much fed up with them". He still becomes frustrated, but he is trying to work out the interpersonal dimension of the frustration in his own way. He feels that during the past few years, among the people who know about his disabilities, he has heard too much well-intended advice of what to do, when what he really needs is the time to figure those things out for himself.

He says, "I'm a long ways from being happy and satisfied, because I've got things I need to work on and I want to reach my goal. I still

want to go back to college, but first I want to improve my English. I'd like to be able to explain some of the things I think about people. I know what I'm thinking and what I see, but I don't know how to explain it, because I don't have the right words. I don't know enough to be able to put it into sentences. But that's my goal, to explain what has happened to me and how I think and see things.

"I'm changing now and learning on my own how to deal with my frustrations. I'm trying to solve any problems right there when they happen, not wait until tomorrow. If it happens at work, say I bump into somebody, I'll explain what happened and let it go at that. Maybe he won't understand the first time, but maybe the second or third time he will. It depends on how good the other person is, how good an attitude he has. And it depends on me, how well I can help him and give him good information. I think we ourselves need to take responsibility to help other people understand. I think we need to learn to explain things and give other people a chance to give us a chance."

The foregoing profile is excerpted from *Living with Deaf-Blindness: Nine Profiles*, written by Carol Yoken and published by the National Academy of Gallaudet College. The book, based on extensive interviews with deaf-blind adults, provides glimpses into such topics as growing up deaf and attending state residential schools; losing one or two senses gradually or suddenly; adjusting to loss and limitations; and associating with families, co-workers, professionals, and friends. It is available clothbound (\$9.50) and paperbound (\$6.50) from Curriculum Development and Research, Gallaudet College, Kendall Green, Washington, D.C. 20002.

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