Hi, my name is Barbara McLetchie, and I’m a professor at Boston College. And it pains me to date myself, but I’ve been training teachers who work with children who are deafblind for the last 20 years, and I’ve been working with deafblind children for the last 30 years. Today I really want to speak to you – the families who are watching this – more from my own perspective as a family member. And there are some major points I would like to make today.

Our Children Are Our Teachers
I’m a parent of 3 children. My oldest son is 30 years old, and he was born profoundly deaf. And what I would like to really share with you as family is that children who are deafblind, or children who face communication problems, are really very, very best teachers. I probably have written and read many articles about communication. I’ve read many textbooks about communication – when I was studying for my doctorate degree. But the bottom line is that I have learned more about communication from deafblind children – from my son and from their family – than I have ever learned from a textbook or from reading research. So if you begin to look at your children as your teachers, you will learn so much about how they communicate. That’s the first point. Our children are our teachers.

Broad View of Communication
Secondly, in order to understand how our children can teach us, I think we have to take a very, very broad view of what is communication, what is language, and what is speech. I always like to think of communication as a big umbrella, and under communication comes language an speech. But also under that umbrella are all of the forms of communication that are not language but are very, very powerful forms of communication that not just deafblind children use – that we all use.

Basically, most of the information that we get – communication interaction – at least 60% comes from body language, comes from gestures, comes from facial expressions. There were many times – we’ve all heard this – that silence speaks louder than words, because our demeanor conveys a message. Think about your children, and think about all of the nonlanguage, or what professionals would call the nonlinguistic forms of communication, that they use and we also use. Change our body position. Our children may kick; they may take food out of their mouth or push it away when they are full. They smile to show us they’re happy; they cry to show us that they’re sad. For some children who are deafblind and have physical disabilities, they may actually respiration to let us know that they’re expired or they recognize that someone new is in the environment. Other children actually may flush – get a little red – to indicate that they are distressed. So those are some very good examples, I think, of nonlanguage forms of communication that we all use, although they’re done with your body.

Nonlinguistic Forms of Communication
Let’s think about some other nonlanguage forms that all humans use. We use objects all of the
time to communicate. If we want more to drink, we might point to a glass. We look at things in a store environment and use pointing behavior to point to objects that we like. We exchange objects with people. Think about all of the times that we have conversation with our friends based upon objects. “I like your new clothes.” “I like your ring.” “I like the new sofa that you bought in the house.” So objects are nonlinguistic, not language, but they are forms of communication that all of us use. Another form of nonlanguage communication are pictures. Now I think one thing that we miss terribly working with deafblind children who have some usable vision is the whole concept of drawing with children. Very often I will trace objects with the child; it’s a very good way to stimulate the vision in a functional approach. And when you involve the child in the process, you’re making language and communication come alive.

Language
Let’s go on and think about, then, we’ve still got this great big umbrella, and you see under it, we have many, many forms of nonlanguage, nonlinguistic communication. Then under that umbrella, yes we do have language. Language is an arbitrary system that means it’s agreed upon. The word t-r-e-e has nothing to do, that resembles a tree, the way a picture could clearly indicate that it’s a tree. So, it’s arbitrary; it is very abstract. Think about some forms that we have for language. Well, we have sign language, we have written language, we have Braille, and we also have speech. But note that speech is only one tool for language. Then if we go back to that big umbrella, we see that language is a tool for communication, and then speech becomes a tool of language – it’s oral language.

So, I think, and I can say from my own perspective when I was bringing up my oldest son, it’s the hope of all of us, as family members, that our children will learn to speak. But I think if we begin to look at everything our children do already to communicate and add to it, we realize that speech is one part of this. It’s a dream that we do not give up, and certainly you will be speaking to your children all of the time when you’re using objects or gestures or signs. But understand that many children who are deafblind will not develop intelligible speech. But every child I have worked with who is deafblind can become a more efficient and very powerful communicator.

I was doing work in rural Portugal about 4 years ago, and I went to a family who was devastated about with their deafblind little boy who was 3 years old. And they said, “You have no reason to be here” – in Portuguese, I had an interpreter – “You have no reason to be here. He can do nothing. He cannot communicate.” And I said, “Well, mind if I stay for awhile, and I did, and it was lunchtime. And the mother began to feed the little boy two things. Portuguese love potatoes, and he was also being fed bananas. And it was very clear that when the mother put the spoon of bananas in the little boy’s mouth; he smacked his lips, smiled, and his mother said, “Oh, you want more,” and proceeded to give him more of the mashed bananas. She went on to feed him the potatoes, which he immediately spit out. And she says, “Oh, you don’t like that. It’s okay; you don’t have to eat it.” So I said, “How did you know what he was trying to tell you?” She said, “Oh, that’s easy. He didn’t like the potatoes; he spit them out. And he smacks his lips when we likes something.” And I said, “That is very strong communication.” And within an hour that mother could think about 82 different things that her child was already doing to
communicate. He did not have formal language; he did not have speech. But he became a more powerful communicator, because his mother recognized everything he was already doing to communicate.

Gaining Attention
Let’s go on to think about normal development in the first year of life. And I like to think about these not just because they occur in the first year of life, but there’s a crucible when we implement communication systems from the moment a deafblind children is born until they reach adulthood and until they die. And if you think about these, they’re all important components of our everyday communication. First of all, think about gaining attention. Without gaining attention of another person, there is no communication. From the moment a normal baby is born, they are, in fact, very, very powerful communicators, and I think all of us who have children can remember when we hear the baby cry – especially if it’s your first – you jump up; you react. You go and interact with the baby. So from the moment that a sighted/hearing children is born, they use gaining attention, and they begin to feel powerful that they have control over another human being. The issue with a deafblind baby is that they may not see the person come; they don’t hear the person’s reaction. So they don’t realize that they have any control. What we have to do is to look at gaining attention and the obstacles that vision and hearing put upon that and to think of very creative ways that we can respond and react. Gaining the attention of another human being is a basic human right.

A lot of early intervention programs and school programs – and I’m sure you’ll see this on your Individual Family Service Plan, or IEP – there’s a lot of talk about cause and effect. I go to a team meeting, and I say, “Well, how do you measure cause and effect?” “Oh, they can turn a switch, and the toy will be activated.” But you know real cause and effect begins at birth. It’s the power that a child has over another human being, and I think that very often, and unfortunately, we forget that. What can we do about that with a child who is deafblind? There are many different strategies. But if the child is in close proximity, touch him when he makes a sound. Many deafblind children may not have a normal cry, or may not be able to cry at all because they have Cerebral Palsy, so we need to look at any motor movement that the child has and interpret that as gaining attention.

With the normal baby, at the beginning, they don’t understand that they have control. But the mother or the father imply intentionality to the cry, and very soon they learn that that cry is useful. If the deafblind children is unable to vocalize – I worked with one little boy who could raise his arms, that’s what we used for his means of gaining attention. We have to be very, very cognizant of what the child is doing and how we can use it to gain the attention of another human being.

Mutual Attention
Think beyond that about mutual attention. Communication, conversation require the attention of at least, again, two human beings. And we’ve all seen these wonderful pictures in ads and on TV that mutual attention is usually conveyed by the mother or the father looking at what? That connection with the babies eyes. When a child is deafblind and has significant vision loss, mutual
attention is often not considered. Some children who are deafblind may, in fact, have physical disabilities, so that when the child’s face turns toward the mother, their reflex is to push away, and the mother may interpret this as rejection. What can we do about that? It will change for each child, but basically we use touch as a very powerful form of communication to make up for the mutual eye gaze. And there is wonderful research to show that with normal blind babies and mothers, when you touch to compensate for the mutual eye gaze, these children develop language and communication skills normally. With little babies, it’s sometimes fun to just keep them cheek to cheek for mutual attention. As the child gets older, and gets into his or her teens, it’s not appropriate to do cheek to cheek, but you may sit with the child, so that his knee or her knee is in contact with yours, so that they know that the attention between two human beings is being maintained.

Acceptance and Rejection
So, we have gaining attention and mutual attention – let’s look at the next thing which is acceptance and rejection. A baby who is a few hours old can tell us when they want more to drink or no more to drink. They will push the bottle away. There are good video tapes that they flay their fingers and turn their heads away. When they want more to drink, they’ll turn their head back. So many deafblind children that I’ve worked with – I’ve gone to meetings, and people say, “He’s too low functioning to tell us ‘yes’ or ‘no.’” If a child can show us acceptance or rejection, or tell us they want more or no more, that is a basic yes or no. It is concrete compared to nodding your head up and down or back and forth. But there is no child who is deafblind who is so challenged that they cannot tell us yes or no. The problem is we don’t give them the opportunity to tell us yes and no.

Imitation
Again, to look at the next component that occurs in the first year of life, and it’s critical to communication throughout life, is the concept of imitation. People often ask, “Well Barbara, where do you start?” We said earlier, it’s easy to know where to start – you start where the child is. In normal development, it’s the mother or the father who imitate the baby first – before the baby is expecting to imitate the mother. Again, it’s like gaining attention. The control of having someone imitate you – that’s a basic level of self-esteem. So we need to start with the concept of: find something that the child likes to do – a motor movement, perhaps a rhythmical motor movement – that you can imitate, so that you enter the child’s world and make him or her feel powerful.

Turn-taking
Then the next component is – once you’ve imitated the child, you being a wonderful conversation. And conversations can occur with and without words. They can occur under that umbrella of communication in nonlinguistic form or in linguistic form. Playing patty cake with a baby or young person is a good example of turn-taking in nonlinguistic communication. But turn-taking is the crucible, as are these others, for future and lifetime communication development. To take a turn with a person means that you share something with the person – that you’re interacting with something together and enjoying the comforting or each other.
Conclusion

I think through Project SPARKLE for sure, you are going to continue to learn many, many communication strategies. The communication strategies will range from the use of objects, to pictures, to signaling behaviors, to gestures, to sign language, maybe to speech, and to written language – either in print or in Braille. You’ll learn about all of these different forms of communication, because all children need a means to communicate. And we need to build on what they already have, so we will consider the forms of communication. But unless we, as family members, really begin with a strong philosophy . . . a philosophy that’s guided by our hearts – and that means by our children, a philosophy that’s guided by a real commitment that our children are our teachers, and we must follow their lead, a philosophy that all children – regardless of the severity of their disability to communicate, and that the crucibles of communication that begin in the first year of life – from gaining attention to the imitation – are important throughout life, and we must think about them in all interactions. So, it’s my hope today with what Linda Alsop called – to take the edge off the nervousness – for me to have a chat with you . . . I think that no matter what we do when it comes to communication intervention, we really must have a philosophy and a commitment. And there’s really no one better to share that philosophy with other team members than you who are the parents and the siblings of children who are deafblind.