COMMUNICATION: PRESENTATION

Robert Stillman

Abstract: Historical background is presented as well as an overview of current programs for those who are deaf-blind. We need agreement on the meaning of commonly used terms, and we need to know more about factors affecting the acquisition of communication skills. Third, we need to learn more about these students to account for learning differences not readily explained by the presence of impaired vision and hearing, that is, knowledge of the cognitive strategies these students employ. We need better preparation of educators who now know little about acquisition of communication skills and even less about students who are deaf-blind. Finally, professionals need to reshape their thinking and techniques since most of these students are now in integrated settings. The goal is effective communication that will result in greater inclusion in society.

Communication is the process of exchanging information. It is the way we share our knowledge, needs, wishes, and feelings. For most of us, communication is effortless. We speak, gesture, and sign, and we assume that those with whom we communicate will understand. And, usually with little diffi-culty, we understand what others communi-cate to us. Communication may seem routine. However, producing sounds and movements meaningful to others and making sense of the sounds and movements others produce is no easy task. We may not remember it, but, all of us went through extensive preparation at home, at school, and with our peers to acquire the communicative skills we have today.

Communication and language require a sophisticated array of cognitive skills and biological structures. Their acquisition is not one of stacking blocks until a tower is built. Rather, it is an interlacing of continually changing cognitive, perceptual, and memory skills; maturing neural and motor structures; and the experience of active, passive, and reactive engagement with objects and others. As a result, the emergence of communication and language has an underlying pattern common to all persons, but its features are individually unique. When we look at the myriad of factors contributing to communication and language skills, we should not be surprised that it is affected by a variety of organic impairments. However, we should be amazed that it is so resilient. Against this background, I will describe some of what we know and some of what we don't know about communicative skills and their

acquisition in individuals who are deaf-blind.

Deaf-blindness is a descriptive category. It is not a category arrived at psychometrically or based on etiology. Individual differences in degree of sensory impairment, age at onset, and the presence and extent of other disabling conditions are enormous. Furthermore, environmental factors including, but not limited to, early and consistent family support systems, the availability of health services and prosthetic and assistive devices, and the calibre of educational programs further expand differences between individuals. In fact, it is not even realistic to consider oneself a specialist without specifying a particular subset of persons who are deaf-blind. For example, my experience has been almost exclusively with students having disabilities in addition to impaired vision and hearing. These almost invariably include cognitive, motoric, and emotional disabilities, the combination of which seems to multiply rather than add to the effects of dual sensory impairments. Furthermore, nearly all of these students became deaf-blind prelingually, that is before the time they might have been expected to become language users. My interest and expertise thus reside largely in nonlinguistic and, for the most part, nonsymbolic forms of communication and in the growing numbers of students who also have severe cognitive, motor, and health problems.

This will be neither an extensive literature review nor a summary of the various devices, assessment procedures, or programs currently in use. Instead, it is a discussion of ideas regarding communication honed from our work with students who are deaf-blind and which now infuse our intervention programs. I will speak from the perspective of having done observational research on intervention with individual students rather than on the broader issues of public policy, systems change, and service delivery models.

Historical Background

To begin, a little history is worthwhile. The growth of knowledge regarding how students who are deaf-blind acquire communicative abilities and what techniques are most effective has been far from linear. It is a tangled history of rapid, abrupt, and sometimes cyclical changes; of fads and flops; and of successes and failures substantiated by testimonials. To a significant extent, the particular approach holding sway depended a lot on the region of the country, the inclusiveness or exclusiveness of the criteria used to identify those who are deaf-blind, and the auspices under which services were offered.

At least five models or approaches to communication intervention have vied for domination over the past 25 years. Each has contributed and each, in a sense, has impeded

progress either through misapplication or dogmatic approaches which failed to appreciate the uniqueness among students who are deaf-blind and between these students and others with sensory or other disabilities.

Of the approaches, only one had its origin exclusively in work with persons who are deaf-blind: the movement program developed in Holland by van Dijk. The other approaches were efforts to adapt techniques used successfully with persons having other disabilities. These include behavioral approaches used with students having severe cognitive disabilities or autism, techniques derived from programs for students having deafness or blindness, and from speech-language pathology and special education in general. Thus, we have taught or tried to teach sign language, gestures, tactile signs, and object symbols. We have systematically and sometimes unsystematically rewarded random and purposeful behaviors and even punished expressions not to our liking. We have tried to emulate normal development and applied the highest levels of existing technology. Not an item on this list hasn't worked for some student and failed with another. It's no wonder that the favorite approach among teachers is eclectic.

It is also important to view our conceptions about communication, not only with regard to programs for students who are deaf-blind, but also in the larger context of the research base in child language. During the time programs for students who are deaf-blind have been established, major and rapid changes occurred. Behaviorist explanations for language acquisition proposed by the Skinnerians were challenged by the Chomskyites who proposed that experience is merely a trigger for neurological mechanisms which organize and direct language acquisition during a critical period. The Chomskyites, in turn, were challenged by Bruner and others who saw the precursors to language not only in a neurologically based "Language Acquisition Device," but in the preverbal behaviors of infants in interactions with their mothers. At the same time, special education and speech-language pathology were discovering Piaget and his conception of the importance of the child in the acquisition of his or her own skills. The field became intrigued by the cognitive domains Piaget described and the possibility that teaching nonlinguistic cognitive skills might speed up language acquisition. There was also strong interest in sensory integration theory (Ayres, 1972) with its premise that motor and sensory losses contributed to cognitive and communicative problems and that enhancing skills in these areas might improve cognitive and communicative competence. Finally, developmental psycholinguists redefined pragmatics to encompass preverbal communications and introduced the field to the concepts of communicative functions, communicative intentions, and

intentional communication (e.g., Bates, 1976), and developmental psychologists became less focused on the principles of learning than the context of learning. Their detailed descriptions of mother-infant interaction, particularly its temporal features, led to introduction of the concepts of reciprocity, turn-taking, engagement, responsiveness, and joint attention (e.g., Kaye, 1982; Lock, 1978; Schaffer, 1977). The microanalytic videotape coding techniques they employed have revolutionized how we observe interactions and collect data.

Current Programs in Communication

Against this backdrop began the work of determining how to help students who are deaf-blind acquire communication skills. In other words, not only were we faced with developing programs for students whose disabilities had previously resulted in denial of services or institutionalization rather than entry into the educational system, but the field itself was in flux. What emerged is rather remarkable and a tribute to the professionals who have contributed to the education of students who are deaf-blind.

Rowland and Stremel-Campbell (1987) described communication as a shared process. They pointed out that if communication between two people is to succeed, they must first share an understanding of the forms or acts which serve a communicative

function and the way these acts are ordered and merged with the context to convey meaning. Second, they must share a common topic or focus of attention. Third, they must share an understanding of the intention underlying each other's expressions. Fourth, they must share a knowledge of the patterns and rules of discourse or conversation. But, sharing in any of these areas cannot be assumed. Often, it must be achieved.

Achieving a shared communication system requires the establishment of communicative conventions. The conventions may be between a few people, a group of people, or an entire culture. Most of what we can say about the status of communication intervention relates to efforts to establish conventions at each of these levels. We may also view these levels hierarchically since, as individuals acquire communicative abilities, they find them most effective with a few, then a group, then many people.

Let me begin with what I see as our major achievements at the level of establishing conventions between a few people. A perplexing problem has been to establish a system of communication when one partner is a sophisticated language user and the other evidences no obvious ability to communicate at all. This is a two-part issue: how to assist students to use actions to affect others and how to assist adults to communicate in ways students understand.

The importance of identifying, interpreting, and responding to the

nonverbal behaviors of students who are at the initial stages of acquiring communication is well understood. The work of van Dijk (1966, 1967), Siegel-Causey (1987, 1989), Downing (1988), ourselves (1984, 1989), and others has provided the rationale, if not always hard data, to support sensitivity and responsiveness as significant factors in assisting students to acquire communicative skills. The key is the assumption that any behavior can have a communicative function. It is the recipient who carefully observes behaviors and the contexts in which they occur and, when appropriate, gives the behaviors meaning through consistent responses. It is no longer viewed as essential to begin by teaching a symbol system or to wait until the student has achieved a certain level of motor, cognitive, or social abilities before we introduce communication. The student is allowed to capture the contingent and contextual relationships between behavior and response through the sensitivity, responsiveness, repetition, and consistency of the partner. This is not to say, however, that we have all of the answers. Disagreement remains regarding how selective to be in responding and how to distinguish potentially volitional behaviors from those which are purely reactive.

Purposefulness or intentionality is a key issue. Any behavior can serve a communi-cative function even if not intentionally displayed. Crying or grimacing in reaction to discomfort, smiling or laughing in reaction to pleasurable sensations, tensing or relaxing in reaction to movement, touch, sounds, or visual displays all communicate to the observer something about the student's state, interest, and readiness to interact. Furthermore, in the case of positive and negative affective displays, the expressions are socially appropriate and so possess an air of conventionality, as well. However, without volitional control, these behaviors cannot be purposely used to affect others and achieve goals. They serve an indexing, but not a communicative, function.

This issue is important because many teachers have not been trained to understand the process of communication acquisition (especially its progressive nature). The result is that they spend considerable time nurturing affective displays which do not contribute substantively to the student's overall development of communicative skills.

We have found that movements are a more viable way of establishing an initial and expandable communication system. A movement-based communication system affords students opportunities to affect others and the environment, to make choices, and to terminate interactions in acceptable, if not conventional, ways. Significant progress has been made developing signalling behaviors even among students whose disabilities are the most severe. Movements over which the student has control are paired with responses appropriate to the movement (e.g., leaning leads to rocking; hand pulling leads to the

spoon coming closer; pushing away leads to a temporary cessation of the interaction). The relationship between a movement and a natural effect sets the foundation for the student to intentionally use particular movements to bring about particular effects and allows others to interpret the movements as signals indicating the student's goal. These movements are not just reactions to stimuli. They are communicative signals shaped by the adult in the context of interactions.

This may sound like behavior modification. But, it differs in important respects. First, there is no arbitrary extrinsic reward or punishment used to reinforce the behavior. The behavior, as with all true communications, brings about a natural consequence. Second, the approach is student centered. Although assistance may be required for students having severe motor impairments, there is no effort to manipulate or force students to perform particular behaviors corresponding either to teacher-generated or conventional systems of signals, or to require students to perform for outcomes unrelated to their interests. Third, the goal is not performing to a criterion. It matters not at all if the student signals on 8 out of 10 opportunities. Perhaps the student is just not interested on a given day. The goal is anticipation. Anticipation is a cognitive skill manifested by behaviors such as signalling which indicate the student has grasped a rule. It means that the teacher has sufficiently organized the student's experiences so they become rule governed. The student expects that in a certain context, as a result of a particular action, or as a result of someone else's action, something specific will occur. Not only does this encourage the use of actions or signals to affect others, but the student can now make assumptions about what is likely to happen under certain conditions and can move on to learn new things. Perhaps most important, it engenders a sense of trust between teacher and student based on mutual expectations and few surprises. This makes the student's world much less random, confusing, and threatening. An approach which enhances the student's ability to act with the anticipation of particular results is important when one considers that the presence of visual and auditory impairments complicates the process of understanding interpersonal and environmental consistencies.

One may also embed signalling within what may be called a protoconversational context. The teacher moves with the student in a movement familiar to the student (e.g. moving the spoon toward the mouth). This may be translated as a request from the teacher to participate. The student's participation in the movement is a response to the teacher's request. The teacher then pauses in the movement. This pause alerts the student that something has happened. It is the teacher's way of asking the student whether to continue. If the student re-initiates the movement during the pause, the

teacher may interpret the movement as a signal to continue. The teacher then responds to the student's communication by re-starting. This is a nonverbal dialogue. Both participants make requests and respond to the requests of their partner. The conversation is embedded in move-pause-move sequences which can be incorporated into any activity. This one simple format includes expressive and receptive communication, signalling, opportunities for choice, turn-taking, and joint action toward a goal. Furthermore, it is conventionalized between the two partners because both use the same form of communication, movement.

Although this approach has sound theoretical and empirical underpinnings, it is sometimes erroneously applied. Interactions which may be typified as "shake-and-wait" where the teacher vigorously stimulates the student, pauses waiting for a response, then restarts the stimulation involve minimal active participation by the student and, at best, afford the student an opportunity to repeatedly practice an already known signal.

At this point, those of you who are most familiar with communication as a shared system of symbols readily identified and distinguished from other behaviors may be puzzled. However, communication in its early stages is not a separate domain. It is a relatively undifferentiated complex of affect and skills. Thus, any one behavior could be called a communication, a social behavior, or a goal-oriented movement.

Certainly, there is much more to say about establishing the foundation for communicative interactions. But, what do we know about students who have a basic repertoire of communicative signals?

Much of our progress has been made in the use of gestural or object/picture systems as described by van Dijk and more recently, the tangible symbol systems of Rowland and Schweigert (1989a, 1989b). Communication becomes conventional when users agree that certain acts, objects, or vocalizations stand for or represent something. Werner and Kaplan (1963) proposed that the ability to represent proceeded along clearly defined paths termed denaturalization and decontextualization. These two concepts have served as guideposts in our efforts to develop gestural and object-based communication systems. Denaturalization refers both in expression and comprehension for the decreasing need for similarity between the communicative act and that which it represents. The continuum ranges from using and understanding only expressions in which the communication and its meaning are the same (e.g., the teacher manipulates the student's hand to pick up a spoon in order to request that the student participate in picking up a spoon, or the student puts the teacher's hand on an object to have it activated), to gesturally demonstrating to pick up a spoon or

gesturing to activate the object, to the most denaturalized or abstract communication, saying or signing to the student to pick up the spoon or signing to the teacher to activate the object.

Decontextualization refers to the ability to use and understand communicative expressions outside the contexts in which they were learned or typically used. There are two aspects of decontextualization, a spatial and a temporal component. The spatial component refers to the degree to which elements of the context define the meaning of a communication. We all use context to support our communications and to clarify the communications of others. However, for many students, the context and the communication are one. The communicative act appears to lose its meaning outside its usual context or in the absence of some aspect of the context especially salient to the student. Decontextualization is the process through which the meaning of the communicative act becomes constant regardless of where it appears and who uses it. This sounds like generalization. But, by conceiving of the failure to generalize not as a failure in learning or stimulus control, but as an indicator of the student's current abilities along the continuum of decontextualization, we can adjust the activities so they demand less decontextualization rather than focusing on further training and generalization probes.

Temporal decontextualization describes the ability to use and understand communications referring to past and future events, as well as the present. Many students who are deaf-blind do not understand references to the future or past. Whatever the intention of the teacher, the student may respond to the communication as if it refers to the present. This may be frustrating to both teacher and student. Again, recognizing that the problem resides in the student's current abilities allows us to consider how and under what circumstances we should attempt to communicate or request communication about past and future events.

What van Dijk (1986), Rowland and Schweigert (1989a), Writer (1987) and we (1984) have shown is that objects or tangible symbols can serve as a mediator in the denaturalization and decontextualization processes. Objects, used either as a step in the acquisition of communicative skills or as an end in themselves, have been quite successful. They provide a simplified and readily expandable and readable communication system, and a system which can be used by the student and the student's communicative partners. Anticipation shelves and object and picture calendars, which are ordered displays of objects or pictures representing the student's activities, provide a way to assist students to understand the organization of the day or even more remote intervals of time. But, more important, denaturalization and decontextualization can be encouraged through the use of progressively more varied and

abstract objects (for some students leading to drawings, pictures, and printed words) and the sequential nature of shelves and calendars highlight the temporal relationship between activities.

However, like other activities, a lack of understanding of the theoretical underpinnings of the approach can lead to misapplication. Sometimes, the object, shelf, or calendar simply becomes another step in a task sequence, its function as a representation, its role in denaturalization, and its communicative value neglected. However, usually these objects and pictures serve as a nonlinguistic communication system understood by many at school, home, and in the community. They especially allow students with limited expressive skills to freely request and to select among options available to them.

Critical Issues

To communicate with all the members of a culture, it is necessary to use and understand their language. This is the most difficult step. That is not to say that many students do not use a few signs or occasional words to express requests or greetings. However, language abilities are much more than that. Acquiring a few signs for an immediately gratifying event such as food, drink, or a stimulating object does not imply readiness to acquire other language skills. However, I must confess to having little

experience with students who are deaf-blind who gained true language fluency, and I have no experience in assisting individuals to retain language skills following later onset.

This leads me to the last portion of the paper in which I will identify some critical issues in communication, the resolution of which may result in enhanced communication skills for students in the future.

First, we need agreement regarding the meaning of commonly used terms such as "communication," "language," "symbol," and "intentional communication." Without agreement we are unable to communicate our successes and failures to others or to assist practitioners to understand what we mean. For example, does communication mean any behavior which can be given meaning by an observer or must there be a volitional component in the expression? Does language mean the ability to use words or signs or must there also be some non-imitative evidence of knowledge of syntax? Is a symbol a mental construct, an external representation of a mental construct, an act, an object, or all or some of the above? How do we define intentional communication among students who, because of sensory and motor impairments or age, do not demonstrate behaviors which identify intentional communication in typically developing toddlers.

Second, we need to know more about factors affecting the acquisition of

communicative skills and, perhaps, learning in general in students who are deaf-blind. Arousal and attention, for example, affect the readiness and ability of students to acquire information. Yet, we have little systematically obtained understanding of strategies to optimize arousal level or how to gain, regain, and maintain attention.

Guess and his colleagues (1988) have demonstrated that many students who are deaf-blind with multiple disabilities spend little time at moderate and alert levels of arousal. Thus, the amount of time during the day when these students are able to participate and learn is limited. Yet, students are often regimented through activities without regard to state, and valuable learning time may be lost because the student's optimal time may not coincide with times the teacher is available. This is especially a problem when one-to-one teacher-student time is limited by necessity or design.

Any interaction characterized by joint participation requires joint attention. We know from studying typical development that lexical acquisition in its early stages occurs when child and adult are jointly focused on a topic, and the child is attentive to the adult's communication. If attention plays a similar role in the acquisition of nonverbal communicative skills, then the elucidation of strategies which effectively gain, regain, and maintain attention are essential.

Third, we lack an operational framework to account for learning differences not readily explained by the presence of impaired vision and hearing. Among these are the use of communication primarily for directive purposes, the substitution of repetitive and stereotyped behavior for exploration and self-guided learning, the apparent barrier in the acquisition of symbolic skills in play as well as language, and the appearance of seemingly inexplicable "splinter skills." Perhaps heterogeneity among students makes a developmental psychology of people who are deaf-blind impossible. But, we are at the point where further advances in intervention must evolve from knowledge of the cognitive strategies these students employ and how their strategies conform to or differ from the way other students acquire knowledge and skills. It is no longer cost effective to pursue theoretical efforts or to compliment ourselves on finding something that works. The clues are there, but the mystery remains unsolved.

Augmentative, assistive, and prosthetic devices have and will continue to have a major impact. However, technology offers tools not solutions. We have spent an inadequate amount of time determining who should use these devices, when, and under what circumstances. For example, there is no consensus over whether augmentative systems should be used to teach new concepts and new forms of communication or to facilitate the student's expression of concepts already known. In many cases, we do not know how the devices are actually used by the

student. For example, is the student using a signalling device to communicate a request, to learn about cause-effect relationships, or simply to generate an interesting auditory or visual display? It is not sufficient for us to assume, without closer scrutiny, that the student's use and our interpretation are identical. We must also evaluate devices to establish whether they are limited to serving instrumental functions or if they allow the expression of a broader range of communicative intentions.

Not all issues regarding students who are deaf-blind will be resolved by learning more about the students. Personnel preparation remains a central issue. Previously, I described a few areas in which misinterpretation of techniques may render them practically ineffective. Certainly, there is much room for upgrading our personnel preparation efforts. In interviews we conducted with teachers over the past several years, none indicated that they received much useful information regarding students who are deaf-blind from their formal education. They also reported little if any exposure to issues regarding the acquisition of communication skills. Much of what these teachers practiced was acquired from their professional colleagues. Even the speech-language pathologists had little background in nonsymbolic forms of communication. Thus, isolation from new developments and inaccurate transmission of information are substantial risks.

But, perhaps the biggest issue of all is figuring out where we fit as we move toward full or at least fuller inclusion of students with disabilities of all kinds in schools and the community. Most of us are used to and comfortable with the status quo. Not that we are by nature conservative, but we have designed some effective procedures for the contexts in which most students who are deaf-blind are now served. For example, by emphasizing one-to-one interactions, we have demonstrated that all students who are deaf-blind can communicate, and we have devised ways to structure the environment and to instruct those who interact with these students so that their communicative skills will continue to grow. But, we have ended up emphasizing the integrity of the individual's program with lesser concern for the value of the student's integration into society. The challenge is to reframe the issue from integrity versus integration to how may we re-shape our approaches so that all students who are deaf-blind, not just the most able, can reap the benefits of greater inclusion in society.

The challenge is similar in magnitude to that which we faced when services for students who are deaf-blind were first established. Twenty years ago, we led the way in establishing innovative categorical programs. We showed everyone that all students, regardless of their so-called "potential," benefited from educational programs. We concluded that students who are deaf-blind deserve and demand inclusion within

the public educational system. We have now reached the next step.

Obviously, communication will play a significant role in the inclusion of students who are deaf-blind in schools and society. There are a host of new issues on the horizon in assessment and intervention and in personnel preparation. We must consider how students will acquire communicative skills in new contexts and, perhaps, with new mentors. In assessment, we will need to redefine functional communication skills. We must also consider how to prepare professionals and peers to instruct and interact with students who communicate in unconventional ways. Eventually, we will need to turn our analytical skills, honed in endless hours of videotape coding and task analysis, to the small issues on which the effectiveness of integrated programs may turn. For example, what contexts, materials, group sizes, ratios, and levels of structure best facilitate interaction, communication, and learning in students who are deaf-blind and among their peers? We will also need to find efficient and effective ways to teach peers (and sometimes teachers, too) that there are ways of communicating other than talking and grabbing.

I don't have the answers. However, I do know that we are at a crucial juncture. We must either lead by showing we can apply the knowledge we have accumulated to the changing contexts where students who are deaf-blind will be served and expected to function, or we can relegate our collective wisdom to the archives while others take the lead. We cannot ignore and, in fact, should capitalize on society's growing commitment to diversity in schools, the community, and the workplace.

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COMMUNICATION: REACTION

Steven Collins

Abstract: We must recognize that communication includes many aspects: facial expression, body language, and cultural rules. From the earliest ages, people who are deaf-blind must be exposed to their "natural" language. They have an internal language and a powerful need to communicate. Those established in the deaf-blind community have the ability to open the world of communication to culturally isolated deaf-blind individuals. Researchers, parents, and professionals need to build rapport with people who are deaf-blind (instead of "using" them for research purposes). They need to learn to communicate on all levels with them. Most of all, they need to listen to and learn from those who are deaf-blind, respecting their experiences and learning their "natural" language.

I want to share with you what a thrill it is to be here at a symposium where we have so many people—professionals and parents—together. Here we are in a forum where a variety of opinions are welcome even though there are strong opposing views. We are all meeting together to benefit the future of children who are deaf-blind. After my presentation some of you will agree with what I have to say, and some may disagree. First, however, I want to tell you where I'm coming from, a little bit about my background. I don't have years of experience as a researcher or as a scientist; however, I have been involved with the deaf-blind community all my life. I want to speak to you from the perspective of a deaf person who has been involved with people who are deaf-blind.

I would like to speak about the great variety we find in this group of people. There are those who have Usher Syndrome Type I, and there are those who have Usher Syndrome Type II. There are those who are deaf-blind and have additional disabilities. Dr. Stillman's paper was narrowly focused on one small segment of people who are deaf-blind: those who have developmental disabilities in addition to being deaf-blind. I would like to broaden the picture to talk about other parts of the spectrum. It is important to understand that there are people who are deaf-blind out there who go on to pursue higher education: college, graduate degrees, and doctorates. Many of these are quite successful, especially when it comes to communication.

When we talk about communication, it's important to talk about language. When we talk about language, it's important to consider where language comes from. We have heard some discussion from parents talking about language, but are they talking about a *natural* language? We need to give some consideration to this because, when people talk about natural language, they only think of English, including speech, signed English, or an English-

imposed system, even if they accept sign language. However, a system that is really natural comes from within the person. A person who is deaf or deaf-blind with Usher Syndrome may grow up in a residential school for the deaf. These people do not have English as their first language: instead, they use ASL, American Sign Language. Many people use the expression "Sign Language," but it is important that when we use it we recognize we are talking about *American* Sign Language, a language that is natural to America.

We see this problem in Stillman's paper. He does not understand all that language includes. It includes so many factors—facial expression, body language, and cultural rules.

One of the greatest frustrations we find in communication with people who are deaf-blind is that they have not been exposed to the proper language. Hearing people, as infants, are exposed to language while in the mother's womb. Before the age of one, they learn to babble and they will continue their development appropriately. Children who are deaf have an inner readiness for a language if exposed to it, but these children have to go along with the language that is available. If the infant is not stimulated with the proper language, it becomes very frustrated. Later on, there can be communities established to provide a shared means of communication. Inadequate research has been done in this area, and those who have been doing the research don't have

the language of the population we are talking about. Their language may only be signed English. As a result, they may not have the full spectrum of communication.

Dr. Stillman, in his presentation, mentioned the need for arousing and maintaining attention for effective communication. This is also true with internal natural language. In order to accomplish this, the speaker needs to be *fluent* in the language, not just *good enough.* If there is fluency, then we will see this advantage carry over into the research. This gives us cause to wonder about the researcher who is not doing an indepth study with language. This person may not have good language skills or knowledge of appropriate physical contact or the appropriate way to relate. People who do have these skills are rare.

Let us talk about the issue of arousing and maintaining attention in regards to children and communication. Even the word "communication" is vague. It includes aspects such as feeling, touching, facial expression, body movement, and the general feeling of rapport. I strongly encourage parents of children who are deaf-blind and professionals to contact adults who are deaf-blind who have a strong language, whether it be, Signed Exact English or American Sign Language.

I would like to point out that there are deaf-blind communities around the country. Even in Washington, D.C. there are local organizations

such as MWADB (Metropolitan Washington Association of the Deaf-Blind). In Seattle, there is WSADB (Washington State Association of the Deaf-Blind). In Pittsburgh there is WPADB (Western Pennsylvania Association of the Deaf-Blind). Many other large urban areas have clubs for those who are deaf-blind. Certainly I won't have time to name all of the communities, but I think it is important to give credit to all of them. I believe language is what causes us to feel like a family, to become very close. We socialize and have monthly functions or meetings. Unfortunately, we don't see parents or professionals involved, and we see that they don't know what is really going on. They end up missing out on many aspects of the deaf-blind community by not being involved.

One of the most important aspects of a deaf-blind community is the culture. Parents and professionals cannot just go into the deaf-blind community. One has to be invited or asked to come. If you can find entry into this culture you will find plenty of meaningful data to help you with your research, but to come in as an outsider and to impose your way in is not welcome at all. It is very important to build rapport with the person who invites you in. Again, my focus isn't only on people who are deaf-blind with developmental disabilities but on a broader spectrum that includes Usher Syndrome Type I and Usher Syndrome Type II, from infants to the elderly.

When we talk about the deaf-blind community and their language, ASL, we must also discuss the oppression which has been in existence for many years, in both the deaf and deaf-blind communities. As Americans, English, or the American culture, is always being imposed upon us. One of the "hot' topics today is multicultural diversity. Some things I can see have not yet changed, but it is now time for change. Early research of the fifties, sixties, and seventies was done on hearing people, then deaf people, and, always as the final category, people who are deaf-blind. People would tend to analyze the issues of those who are deaf-blind only when comparing them to the issues of those who are deaf. Now that we are in the nineties, we need to take a look at the researchers, the people trying to analyze and gather information. We need to find out if they have a language base or the necessary background. For example, we have yet to see adequate research on the tactile methods used by people who are deaf-blind. Several people are successful at communication, especially those who have graduated from the Perkins School. My point is that researchers should not be *using* these people; they should be *working with* them. As a deaf person, I have dealt with, communicated with, and enjoy a rapport with hearing people. They feel able to ask me questions about language or culture because I have "invited" or "welcomed" them. I want to see more research done and more papers being published. I also want to see publications with

adequate input in them from successful adults who are deaf-blind.

At this time I would like to share one success story of the deaf-blind community. A man in his 40s arrived from another country in which no one had understood the etiology behind his deaf-blindness. For 40 years, he had been considered to be a person with many limitations—even developmen-tally disabled. He was shipped off to the United States and found himself in a town which had a large deaf-blind community. He was welcomed into this community. Although he wasn't able to use American Sign Language or even an expressive form such as body language because he had been confined for 40 years, he still had an internal language and a powerful need to communicate. Throughout his life, people who dealt with him had not stimulated him. However, when he got involved with the deaf-blind community, he entered a new situation. At a deaf-blind camp, he encountered a deaf person whom he had never met before. When these two people met, language occurred successfully. It turned out that they were intelligent people in their own fields. They could communi-cate. The person wasn't developmentally disabled at all. In fact, there were no additional disabilities. He was just a regular person with Usher Syndrome. Many of the most valuable years of his life had been wasted because of not having his language needs recognized. For hours upon end, these two individuals were able to talk and communicate and participate in other activities. I have

since seen this particular person communicating fluently. He was able to communicate because he had an internal language readily available.

Some of you in our audience are parents, and some of you have been involved in the professional arena. You can't help but notice the problems of people who are deaf-blind. When I talk to you, I speak as a deaf person. I think I can share with you a parallel. We can look at what has happened with people who are deaf over the years and see a striking similarity. For years, people didn't recognize the potential of people who are deaf.

The problems we face are significant. We all can do better. One important way to overcome these problems is to support and learn from the deaf-blind community.

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