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#### **ABSTRACT**

This paper presents a brief history of communication intervention and describes recent developments which have brought about shifts in intervention focus, perspectives, and strategies, especially with people having severe disabilities. In examining how communication is important to a good quality of life, the paper points out that the real point of communication is membership in society. The concept of membership is explored, including the ways in which individuals construct stories that make the communication acts of individuals with severe disabilities commonplace and socially valuable. The paper concludes that efforts to foster communication should shift to making sure that these efforts actually result in individuals achieving social membership. (Contains 20 references or suggested resources.) (Author/DB)



# Is Communication Really The Point? Some Thoughts on Where We've Been and Where We Might Want To Go

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This paper  $\frac{1}{2}$  presents a brief history of communication intervention and describes recent developments in the field which have brought about shifts in intervention focus, perspectives, and strategies. In examining how communication is important to a good quality of life, the author concludes that the real point of communication is membership in society. The concept of membership is explored, including the ways in which individuals construct stories that make the communication acts of individuals with severe disabilities commonplace and socially valuable. The author concludes that efforts to foster communication should shift to making sure that these efforts actually result in students achieving membership.

When I was first invited to prepare this paper, I was sure it was a mistake. While for some time now I have actively promoted inclusive schooling and community lives for people with severe disabilities, as a teacher, a teacher of teachers, and a parent of a young man with severe disabilities, I am certainly not, by any stretch of anyone's imagination, a specialist in communication. I, like many of the rest of you, read and listen to the others participating in this symposium in order to learn what I can about communication, how it works, and how it might work better for people with significant disabilities.

I was intrigued, however, by the topic I was offered: The Role of Communication in Program Evaluation Based on Student Outcomes and Quality of Life My first task was to try to Measures. figure out what that meant. So let me begin to undertake the task I have accepted by briefly reviewing where I think the field has been in trying to teach language and foster communication with people who do not acquire that ability naturally.

#### From Acquiring Language To Fostering Communication

There have always been people in our midst who could not speak. earliest responses to such individuals frequently involved the assumption that

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failure to speak was caused by a more fundamental failure to think. Gradually, we not only began to realize that speaking and thinking were separable abilities, but also to appreciate the awesome complexity and consummate skill with which children acquire the ability to speak (Moskowitz, 1978). Children learn but are not taught Instead, they seem quite literally to acquire language in the act of doing language, supported in their efforts by the others in their environments. And while psychologists, educators, linguists, and philosophers still try to better describe and explain what children so simply and elegantly do, it is clear that we already know a great deal about the acquisition of language.

Perhaps one of the most important things we have learned is that language acquisition depends upon communication. Infants and young children find ways to make sense of and deliver messages about themselves and their worlds long before they are able to shape words or even recognizable sounds. However, we understand less clearly the acquisition of communication or how communication operates to foster the development of languages and to help people make meaning (Bruner, 1990).

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Within our own small field, there has been a substantial increase in understanding why many children and youth with severe disabilities neither speak nor communicate effectively and what to do about this human limitation. The most concise way to describe the changes of the last ten years or more is that our focus has shifted first from teaching people to speak, then to giving students language, and now to helping students communicate.

Many of you will remember the imitation training we used in an attempt to get students ready to repeat our words. We flapped our arms, patted our heads, and rubbed our stomachs during hundreds of 15-minute lessons so that students would repeat "buh" and "ma." worked, we proceeded to naming -- first objects, then pictures, then symbols, then words. When it didn't work, we assigned the student to an assistant or volunteer who kept flapping, patting, rubbing, and recording zeros on our data sheets, while we specialists went on to another student who seemed more promising. Sometimes we started to hide and uncover things we thought the student liked, thinking imitation too advanced a task.

About 15 years ago, we began to offer alternative languages. Sign language, manual signs, blissymbols, and even rebuses all offered new paths to language acquisition, even when the language did not match our more conventional forms. Most of us teaching during that period spent hundreds of hours building language boards as an alternative to teaching speech. There was a real art to it, and many boards were quite aesthetically



pleasing with their bright colors, overlays, and color-coded groupings of nouns, prepositions, verbs, and names. Every child needed his or her own board, but in most cases the only thing that personalized a language board was the size of the squares, carefully determined based upon the student's pointing mode and accuracy. Even the proper names were pretty much the same, at least for language boards within any one classroom.

It took until the early 1980s for us to realize that all the little zeros and flat graphs still collecting our data probably did not represent so much our students' limits or even the failure of our teaching but, rather, a serious gap in our perspective. We had failed to look at either speech acquisition or language learning from the student's point of view.

As adults, we have lost most of our aptitude for acquiring language as a tool for communication. The remarkable skill that children wield so effortlessly is almost fully atrophied in the youth or adult who, for example, tries to learn a "foreign" language. When we attempt to recall how we learned language, most of us only remember the grammar lessons of elementary and middle school, which sought to teach us the rules of "correct" or "standard" language usage. Just as we cannot really remember how we learned to walk, we cannot recapture the intense effort we expended dissecting the cacophony of sounds we encountered as young children into the minimal separable units of sound and meaning (Moskowitz, 1978). Neither can we recapture why or how we then induced rules for recombining those sounds and meanings into words, meaningful sentences, and patterns of dialogue, or -- more importantly -- why we wanted to. It is this memory lapse, I think, that led us to organize our interventions more like the grammar lessons of fifth grade than the natural action research of the young child.

With the 1980s we finally began to shift our efforts from acquiring language to fostering communication. How does this student communicate now? What meanings do students need to communicate? What forms do they use to communicate? These are all questions that guide our current intervention practices.

In the words of the National Joint Committee for the Communicative Needs of Persons With Severe Disabilities (1992), we now seek to "facilitate attainment of socially effective communication repertoires" (p. 4). We have realized that we cannot always "fix" faulty language development, but we can perhaps reverse, or circumvent, the deleterious effects that severe disabling conditions can have on an individual's ability to communicate with others. Our focus has shifted over the past 20 years from acquiring words and languages to the outcome of "socially effective communication repertoires" (National Joint Committee, 1992, p. 4). Our technology for achieving this outcome is impressive.

As a summary of this brief account of our recent history, let me identify the three features of that technology that I find most important.

Feature 1: Shift in intervention focus. Rejecting an exclusive focus on the forms of communication -- whether

sounds, words, semantics, or grammar -we now emphasize analyzing and teaching
communicative functions. We now believe
it matters less how a person communicates
than that they successfully request, reject,
and comment in ways that affect other
people in their environments. This shift
has opened up many new possibilities for
the formats people might use to communicate, and we have consequently expanded
our cleverness at helping people communicate in nonconventional but functional
ways.

Feature 2: Shift in intervention perspective. To function communicatively, some of the unconventional ways in which people express themselves depend upon others' understanding their "communicative acts" as communication and not as pathology or recalcitrance. We now try to pay as much attention to the activities and other people in the communicative milieu as to the person with disabilities we are seeking to assist. While the point of view still begins with the student, our broadened perspective must also encompass all others in the environment. We are encouraged, for example, to analyze people and environments for how they "invite, accept, and respond to communicative acts by persons with severe disabilities" (National Joint Committee, 1992, p. 4). It is not just what is said and why it is said, but also what happens to what is said that matters. Communication is facilitated when people's contexts are rich in opportunities to communicate and be understond.

Another aspect of this perspective shift is a renewed emphasis on using the information and interpretations of a wide variety of others to figure out more creative ways to facilitate desired "communication repertoires." The very complexities of human interactions and social environments require the focused attention and creative thinking of many to manipulate matters in ways that support people with severe disabilities to be successful communication participants.

Feature 3: Shift in intervention The shifts in focus and perspective have naturally led to a shift in intervention strategies from ones that relied on a good deal of inference -- what we are doing right now at this table with these materials will help this child communicate later to other people in another place - to ones that eliminated or at least greatly minimized inference. Preferred "learner-oriented" intervention strategies rely upon "real-world" places, natural activities, and typical people (e.g., Warren & Rogers-Warren, 1985). seem to be trying to recapture some of the young child's natural action research approach, which is action research precisely because it is so dependent upon context.

Of course, there is still much to be learned, both about language learning and about fostering communication. Even the briefest review of the available literature reveals a number of ongoing debates (e.g., Calculator, 1988; Kangas & Lloyd, 1988; Reichle & Karlan, 1988; Romski & Sevcik, 1988). Are there any prerequisite abilities to even this new conceptualization of augmentative communication? What is the relationship between communicative functions and symbol meaning? What do you do when the disabled student is not an



active participant in the communicative exchange? Are some of the higher-tech, and more expensive, devices and systems justifiable when compared to the benefit obtained by the person with severe disabilities? Is there any role for simulated teaching and multiple trials? How many augmentative communication modes are enough, and are we using the right "rules" for deciding which and how many? How do we get communicative partners to increase opportunities, respond more appropriately, and understand more quickly? Just how do we get groups of professionals to work together?

I expect that in one way or another the field will eventually discover answers of a sort to these and other questions. The discussions I find most intriguing are those that describe all the ways in which even our new ideas and technologies are not getting it quite right (e.g., Calculator, 1988). Even though we must make our best guesses about meaningful vocabulary, there are still too many nouns and verbs in our augmentative systems that students need only to obtain our reinforcers. While we seek ways to embed communication opportunities in existing activities, we too often respond to a child's point, head nod, eye gaze, or noises by telling them that we understand what they mean, but they must point it out on their board or use their device. We still spend a lot of time asking our students redundant and meaningless questions just to get them to answer.

Sometimes, in fact, we seem to get things more wrong than right. Some colleagues of mine at the University of Oregon recently began a federally funded research project to investigate the impact of assistive technology on children's lives both inside and outside of schools. Their first challenge was to find "users" of assistive technology, especially "devices" technology. Within a few weeks they had redefined "user' to "possessor" of assistive technology. Of course, even "possessor" turned out to be inaccurate, since they found too many devices languishing in the corner, far enough from being in the possession of the intended user to completely exclude, and perhaps obviate, real use.

I suspect it is these rapid changes in our approach to speech, language, and communication for students with severe disabilities, combined with the continued "error patterns" of practice that we all still experience, that gave rise to the topic I was offered. My task in this paper, then, is to reflect upon the role that fostering communication plays in improving the quality of students' lives. Put slightly differently, how is communication important to a good quality of life, and how do our current practices support that agenda?

# From Fostering Communication to Achieving Membership

Implicit in this topic and explicit in the guidelines of the National Joint Committee (1992) -- which are presented in Appendix A of this volume -- is the assumption that communication is central to a good quality of life:

> Any consideration of quality of life must take into account the degree to which individuals can



effectively communicate with, and thus be a full participant in, the human community in which they live. Communication is, then, both a basic need and a basic right of all human beings. (p. 2)

The logical extension of this assumption is that improving communication will improve quality of life. I will use the rest of this paper to explore the question, "Is communication really the point?" because I think it is not.

Instead, I will argue that what we really seek is not "socially effective communication repertoires" at all, but membership. And not just any kind of membership will suffice, only participatory, socially-valued, image-enhancing membership. The purpose of all of our interventions, programs, indeed, schooling in general, is to enable all students to actively participate in their communities, so that others care enough about what happens to them to look for ways to include them as part of that community. While communication certainly aids that agenda, it is not the agenda, and that has implications for how we work with communication functions, communication acts, and communication partners, because while communication seems to ground language acquisition, I believe membership grounds communica-Satisfying, active, contributory tion. membership depends upon fostering the kinds of interest, shared meanings, and relationships which upon meaningful communication must be based.

Unlike communication, membership cannot be reduced to acts, forms, functions, or repertoires. Membership

cannot be predicted or controlled; it must be conferred. We can join or affiliate, but we only become members when the group creates a shared definition that incorporates us, including us as a meaningful part of the collective attention and activity. Membership is not achieved cumulatively in bits and pieces of acquired capacity or through certain interactions rather than others. Membership emerges from the actions between people that are borne of interest, belief, and trust, and it is captured in the stories people create to give meaning to their experiences.

In describing membership in this way, I am drawing upon an interpretive view of the world (Eisner, 1990; Ferguson, Ferguson, & Taylor, 1992). Interpretivism seeks to explore the complexities of our experiences by discovering and understanding the various stories we tell to nake sense of those worlds, as well as the processes we use to create our explanatory narratives. An interpretivist perspective is somewhat unconventional in special education, because our field has long depended upon an objectivist approach for investigating and explaining life and its experiences. Objectivists tend not to be satisfied with stories, because they have too much particularity about them. Stories do not control variables very well. Stories are slippery and individualistic, subjective and judgmental (Ferguson, Ferguson, & Taylor, 1992). Yet all of that is precisely why an interpretivist perspective can illuminate the ways in which fostering communication can still fail to achieve membership. Let me illustrate with some stories about membership and how it operates.



Story One. Tuesday's beginning drama class mostly offered lecture/ discussion with a few exercises for variety and practice. First, Rick introduced the notions of "high-centered" and "lowcentered" personalities. He asked students to adopt one of these generic personae and answer questions "in character." After a few exchanges, Rick asked the class to reflect upon how they were depicting these two personae, generating a good deal of discussion about stereotypes and class distinctions. Ethan sat quietly, sometimes leaning back to look at ceiling lights, occasionally yawning, not closely watching Rick, but seemingly listening. wandered as he talked and questioned. When he moved near Ethan, he smiled and touched him warmly. At one point, while framing another question for Curt, Rick picked up Ethan's handkerchief and wiped away the wetness that oral motor impairments constantly created around his mouth.

After several students' turns at the exercise, Rick reminded Ethan that he was going to ask him a yes/no question and that he wanted him to answer in either a loud or a soft voice. More questions, first to Annie, then Paul, then Sheila: "Do you think of yourself as smart?" "Do you think of him (pointing out another student) as smart?" "Stupid?" "Is black your favorite color?"

Rick approached Ethan and asked, "Do you like red?" Ethan replied, "Do you like red?" Rick tried again, only to have Ethan repeat the question. Nora offered assistance, saying to Ethan: "Listen. It's a question. Do you like red?" Ethan still repeated the question. Both

Nora and Rick tried to ask the question a different way, and after three or four more exchanges with both Nora and Rick, Ethan finally offered, "I like red."

Rick asked Nora to explain to the class what had just happened. "Sometimes Ethan doesn't understand what information a questioner wants," she explained, "but he knows that he is supposed to answer, so he repeats what he just heard." Rick added that repeating is Ethan's way of "letting us know that he doesn't get the point, and we have to try another way to help him understand."

This led Rick to a larger point about communication and how important it is to actors on a stage. He pointed out that, as actors, they are going to need to communicate a great deal about a character very quickly and briefly, but they will not enjoy the luxury of having an audience that can tell them when they don't understand. "Ethan," Rick concluded, "can help us all learn how to imagine what might not be communicated, so we can discover all the ways of communicating that will help more people understand what we are trying to convey with our character."

Later in the term, when Kim and Sharon were planning the combative scene that would be their final for the unit, they struggled with how to include Ethan. The scene itself wasn't so difficult to create: Ethan would be walking to a snack bar with one of the young women, when another would approach and kick at his wheelchair, telling him to "get out of the way!" They needed an epithet, however, and that was more difficult. Both students approached Nora and Rick: "What names could/should we call Ethan?" they asked,



worried about being inappropriate and hurting Ethan's feelings. Rick responded, "Call him the same kinds of names you would call your other friends." Both looked unsatisfied with this answer but, after a pause, accepted it and returned to the rehearsal.

Watching the interaction, I wondered if they weren't really trying to ask if it was okay to call Ethan "retard" or "crip." The teacher's response seemed to confuse them, in part because these might very well be the names they would use with other friends. They decided on "jerk," but I think their unspoken question well illustrates that it is the stories we create about the contradictions and dissonances of our experiences which really determine the meanings that get exchanged in our communications with each other.

Story Two. Irene sat Zack in his chair, and a little boy came over and set a puzzle on Zack's tray. He stood next to Zack at a desk with a puzzle of his own. First, he dumped out Zack's puzzle on the tray, and then he dumped out his puzzle on the desk. He didn't acknowledge Zack in any way, but was just very matter-of-fact about what he was doing. Zack grinned at the sound of the puzzle pieces hitting the surface of his tray and picked one up and looked at it. He wiggled it back and forth and tapped it on his tray. The little boy began putting his own puzzle together. Two other boys were playing with large blocks on the floor next to Zack's chair.

I couldn't resist going over to Zack's puzzle buddy and asking him if he had noticed how Zack had smiled when the puzzle was dumped on his tray. He looked at me seriously, picked up another

puzzle, and dumped it out on Zack's tray, then bent over to watch for Zack's reaction. Zack smiled again. A glimmer of a smile crossed the boy's face, and he dumped out a third puzzle on Zack's tray. Then he went back to working on his own puzzle. He hadn't said a word.

Soon the little boy with Zack was putting together his puzzle on Zack's tray table. Zack watched and grinned. The two boys building the blocks on the floor next to Zack's chair had started to weave the blocks around his chair. I walked over to ask them what they were building, and they said it was a train track. Another boy came over and started to do puzzles on Zack's tray, too. A third boy walked up to Zack, leaned over to look into his face, and said "Hi, Zack!" Zack smiled at him, and the boy rubbed Zack's head. This was the same boy I had seen sitting with another student from Zack's special class in the lunchroom.

The two boys building the railroad track wrapped it all around Zack's chair. I don't know if that was intentional or if it just happened because they were working in a confined space, but it made me smile. Zack didn't even know that they were there. Or maybe he did. Maybe he grinned so often because he was surrounded by activity and people.

From time to time Zack dropped a puzzle piece on the floor. Not saying anything but sometimes smiling at Zack, his puzzle partner picked up the pieces and put them back on the tray. The boys building the track were getting bombed by puzzle pieces. The pieces fell on the train track all around Zack's chair. The boys also picked them up and put them back on

Zack's tray. I went over to the boys and told them that, to me, Zack and his chair looked like a mountain and the puzzle pieces were snow falling from the mountain. They gave me odd looks and went back to playing. I suspected the bombs metaphor would have met with more approval.

## **Creating Membership Stories**

Achieving membership for children and youth who have severe disabilities is challenging to be sure. Yet the people surrounding both Ethan and Zack were constructing stories that included them as members despite their differences. In Zack's case, this happened almost entirely without words and certainly without the offered stories of adults: mountain indeed!

The boys were interested enough in Zack to play nearby. One boy experimented and then adopted turning out puzzle pieces on Zack's tray as part of his play. We don't know why Zack smiled or exactly what the boy made of that smile, but it was enough in this scene to change the boy's play to include Zack just a little more. Perhaps this small change in his play agenda encouraged the other boys to build the track a little closer to and then around Zack's chair.

The scenes from drama class occurred early in Ethan's affiliation and illustrate the interpretive procedures people use to make sense of departures from our cultural expectations commonsense beliefs, and norms. Ethan, like all Rick's other students, had a role to play in class activities. Ethan was asked a simple

yes/no question. Why didn't he answer that way? As teacher to student, Rick's relationship to Ethan created the context that required him, with Nora's help, to make Ethan's unconventional response to the simple yes/no question meaningful to the group. I think it is interesting that Nora and Rick created two explanations. One stressed Ethan's interest and similarity: "He knows he is supposed to. and he wants to, respond." The other translated Rick's and Nora's interpretations of Ethan's "mistake" into a point about the task of acting: "It is difficult to communicate quickly and accurately about your character."

Let me share one more story that illustrates in a different way the importance of relationship, interest, and shared meaning as a foundation for membership, communication, and language.

Story Three. "People began filtering into the room in small groups. traditional light wood tables were arranged in a large "U," leaving a huge empty space in front of the speaker's desk. The room, like almost all the rooms I've seen in Finland, was light, airy, and modern. The windows looked out onto the frozen lake through the nude birch trees and scattered pines. The seminar participants arranged themselves around the "U" in their working groups: people from Jyvaskyla at the bottom of the "U" on the right, Joensu on the left. contingent from Vasa came late and filled in the left corner and a few seats of the window side of the room. There seems to be no one from Helsinki University's Special Education Department."

Thus began the fieldnotes I created as an illustration for my presentation the following day to faculty and graduate students from the four universities in Finland that have departments of special education. I expected to understand none of the proceedings, which would be in Finnish. After nearly three weeks, I still only heard the staccato cadence of the language that always reminded me of a march. All Finnish words are pronounced with emphasis on the first syllable, I had learned, but only a few words spoken in isolation, like "kiitos" or "hei" or "paivia," carried any meaning for me.

Still, I wanted to have an illustration of jotted notes collected during an observation in preparation for writing fieldnotes. I also needed something to keep me alert and attentive during this first afternoon of the seminar. It seemed important to be present and interested even though the proceedings were in Finnish, because each of the participants had already been exceedingly gracious about speaking to me in English during my visit.

The afternoon's presentations were quite formal. With only one exception, the speakers sat behind the desk and spoke using no illustrations, except perhaps verbal ones that I could not decipher. Audience members took few notes and seemed to provide very little nonverbal reaction to the speakers, something I had noticed during my own lectures as well. After the second presentation, a period of questioning and exchange occurred among three or four of the students and two of the professors. As I listened and watched, trying to capture

in my jottings who spoke for how long in what sequence, I quite suddenly realized that I knew exactly what they were talking about!

The students were criticizing their system's provision of faculty support for dissertation research. Another point of contention was what the students, and perhaps one of the professors, believed to be a narrow definition of "accepted" research methodologies. Many of the students wanted to explore, for example, qualitative research methods and interpretivist research traditions but felt thwarted and discouraged.

I had not deciphered a single word of the discussion, but the messages of body language, intonation, humor, and pacing, more present in this animated exchange, together with my knowledge of these people and their work which I had acquired over nearly three weeks of lectures, casual chats, and planned tutorials, replaced the mysterious strings of sound with meaning. Later, during dinner, several participants asked me how I had fared for so long a time understanding nothing. When I recounted what I believed I had understood despite my language disability, they confirmed my interpretation and, expanding in English, enriched my understanding with recollected and embellishing details. Thus, for me, having established membership, fairly complex communication occurred even without language.

## The Making of Membership

Our experiences and memories of our social worlds are powerfully



structured, not just by deeply internalized stories of how our world operates but also by the historically rooted institutions of our culture, including such institutions as "special" education (Bruner, 1990). When our deeply held beliefs and explanations are challenged by people and events, we create stories to explain the dissonance. Many people with severe disabilities pose a unique challenge precisely because they do not obviously share our explanatory stories. At the same time, they possess dramatically different capacities for entering into our efforts to create shared meaning. They represent dissonance that must be resolved.

In a study that explored accepting relationships of people with severe disabilities, Bogdan and Taylor (1992) found that nondisabled partners conferred membership by creating stories that (a) attributed thinking to the other, (b) saw individuality in the other, (c) viewed the other as reciprocating, and (d) defined a social place for the other. surprisingly, their stories focused not on those behaviors that might be thought most similar between disabled and nondisabled partners, but on those most dissonant. Partners in such relationships created stories of possible worlds where the exceptions made sense. Expanding commonsense beliefs, so that it is sensible to repeat what one hears instead of responding to a yes/no question, is how even very disabled newcomers become incorporated as members of the group. In relationship story-making way, partners of people with disabilities become co-creators of their partners' cultural identity. Quite literally, we define who persons with disabilities become in our social worlds based not just on what they do, do differently, or fail to do, but based on who they become through our stories.

This story-making process always occurs in one way or another. What the resultant story may not assure is the kind of active, socially-valued membership we seek for people with severe disabilities. Teaching people an appropriate response to another's unconventional communicative acts, or how to create an opportunity for a communicative act, only supports this kind of full membership, if the nondisabled partners already have enough interest, curiosity, and meaning to create a story that makes the different communicative exchange commonplace and socially valuable.

In a recent book Jerome Bruner offers a metaphor I find particularly helpful for illustrating how membership grounds communication:

When we enter human life, it is as if we walk on stage into a play whose enactment is already in progress -- a play whose somewhat open plot determines what parts we may play and toward what denouements we may be heading. Others on stage already have a sense of what the play is about, enough of a sense to make negotiation with a newcomer possible. (Bruner, 1990, p. 34)

It seems to me that children and youth with severe disabilities are always stepping onto the stage of an ongoing play as they move out of isolated worlds to join our



classrooms and communities. Although they may not ever completely divine the script, others' understandings of the possible roles and outcomes they might fulfill determine the inclusion that gets negotiated. In one way or another, people with disabilities become members of the company.

Sometimes, however, this inclusion may not always be a membership that is characterized by active, valued participation and status in the group. Often, deeply embedded social structures and cultural histories can limit and shape the range and type of stories that get told. Think of what it meant to be female 20 years ago. There was a dominant social construction of what was and was not feminine or female. This, of course, does not mean that there were not always many women who had very different interpretations, different social constructions. Similarly, for people with disabilities, our history of social exclusion is grounded in a set of stories that everyone seems to agree with so completely that no one notices any longer that they are, in fact, stories.

As members of the social play, those of us interested in the kind of membership created have an opportunity to influence that construction. If the script about disability --- the commonsense beliefs held by other players -- permits only passive participation in the chorus, for example, or requires that disabled members be "cared for" instead of "cared about" as active participants, no amount of intervention on the communicative act's form, or the ability of other players to invite, accept, and respond, will substantially affect the kind of member-

ship that is achieved. Thus, it is our task to replace the old, taken-for-granted stories with new ones that offer more possibility for richer membership.

## Keeping the Point in Focus

Membership is the point that communication merely serves. We must first understand how others negotiate the newcomer's role, what explanations they create, and what meanings they ascribe. Only then can we foster the kinds of communication attempts that result in full and active membership. We need to shift our efforts from fostering communication to making sure our professional efforts actually result in students achieving membership. Let me suggest three things that might help us all - but especially those of us who are professionals -achieve a shift to membership as the essential outcome in which communication, no matter what form it takes, enhances the relationships of membership rather than takes on the task of creating them.

Create your own stories. Our own professional perspectives, dependent as they are on reducing the problems and solutions of practice to effectively managed components and strategies, can easily miss the bigger picture of membership. Before we expect others to incorporate a student with disabilities by adjusting their own communicative behaviors, we should try to create our own stories of how this individual's differences might be made commonplace, not in our labs, therapy rooms, or even instructional activities, but in the playgrounds,



hangouts, and pathways of active community life. Apart from our professional roles, in the community parts of our own lives, how would we construct this person's membership? What would be our sensemaking story? Does it challenge or accept dominant stories that might be limiting or patronizing?

I remember taking a young friend to the downtown Saturday Market once. Each Saturday from April through Christmas local farmers, performers, artists, and craftspeople set up booths on two downtown park blocks, creating a uniquely Eugene community event. Always a little challenging to commonsense expectations, my friend became on this occasion upset enough to begin screaming. She fell to the ground and began bashing her head on the pavement. Another woman approached, reaching toward her and chanting words about faith, God, and religion. My friend paused, as if joining her prayers. Unable to join in the explanation the woman was creating around my friend, I was nonplussed and retreated from the scene. People moved by, some shrinking, some sympathetic, some pitying in their demeanor and reaction. A couple of people stopped and joined the exchange. I was merely embarrassed, having no way to be matter-of-fact about my friend's outburst.

I've wondered since how I might have made this woman's ways of being in the world a more commonsensical and safe part of our sharing encounters. Perhaps she needed to spend more time on the sidelines, absorbing the stimulation of the Market before moving through and trying to react. Perhaps her only way of

participating in such experiences was from the edges, where her own sense of place could be clearly identified and managed. I might have found the stranger's religious explanation for my friend's behavior unhelpful, but what mattered was that I had nothing else to offer (except restraint) that might have led to ways of interacting with her that resulted in a social place, even a peripheral one, in this regular community event.

Sampling our own nonprofessional perspectives can help us to imagine others' possible constructions of people's differences and to incorporate them as part of our interventions, perhaps minimizing the missed communications our observations so often document but fail to resolve. I might not have imagined the religious explanation, but had I thought about Saturday Market more broadly, I might have remembered that many people come to Saturday market to shop, eat a little, listen to music, and spend time. I might have also remembered the people sitting on the grassy areas and stone seats, watching and commenting on the ebb and flow of the Maybe they were just pausing from their shopping, but they might also have been uncomfortable with the crush and noise of the crowded sidewalks. preferring to join from the sidelines the community of both shoppers and time I didn't know whether my spenders. friend was a shopper or a time spender, or whether the edges or the middle might be her preferred vantage point. I had not listened either to her or to others who knew her interests, preferences, and choices and so had no stories for going to



Saturday market that might have incorporated my friend.

Listen for the stories of others. Achieving membership as I have described it here requires that we improve our capacity to listen carefully to all the others creating stories that explain our students' differences as commonplace. Sometimes, of course, we may not be able to understand the story created. Zack's playmate seemed to be finding a narrative of shared meaning that was not very obvious to the The observer did, however, observer. notice enough of the interaction nuances to realize that a story was being created that incorporated Zack as a member of the puzzle play in some way. At least one boy understood enough about who Zack was as a person to find a social place for him in the game. These constructions of others are often idiosyncratic, replicable across others in the setting, but, for all that, these constructions are no less important to the creation of membership and eventual meaningful communicative exchange among all present in the context.

Listening completely, however, requires that we rest our professional perspective long enough to be able to hear the simple but powerful constructions offered by all, including the most ordinary and unsophisticated among us. Ordinariness is the stuff of membership, because peers, siblings, moms, dads, and folks are the membership partners that matter most in the scheme of things.

If we fail to listen in this nonprofessional sort of way, we risk creating professionally conceived and designed interventions intended to aide both communication and membership but

which serve instead to crush fragile membership beginnings. The observer's mountain metaphor is a small example that, in Zack's case, was safely ignored by Imagine what might have the boy. happened to the puzzle play, and the small smiles, if the observer had first coached the boy in three strategies for inviting communicative acts from Zack and then provided him with feedback about the success of his efforts. The boy might have begun to create an explanation of Zack more characterized by professional dimensions of deficit and remediation - "Oh, he is different, and we have to act in special ways to help him" -- than whatever guided him to so matter-of-factly set up his play so that Zack was in the midst of it. Perhaps the only difference that mattered was that Zack had a tray that made it easy for him to puzzle play. Flat surfaces and puzzles go together.

Our professional techniques work best when they can enhance what is already going on naturally, including how people are creating meanings about the differences our students present to the situation. Pointing out to the boy that Zack smiled when the puzzle was dumped on his tray was just the right amount of professional intervention to encourage the exchange already begun. The important point for membership is that the boy had sufficient interest to turn out the first puzzle. The observer's comment did not capture, it merely nurtured, his interest to try a second and third time for Zack's answering smile.

Proclaim the value of those whose stories so often go untold. There will still be some few students so unique, so differ-



ent, that none of the available cultural, historical, professional, or institutional explanations will provide raw material for the commonsense membership stories we hope to see achieved. It is these few individuals who need not so much our professional expertise and technology as our narrative insight to help the others in their midst construct a meaningful membership role. I have seen able teachers simply ascribe meaning and, in so doing, help others see a very disabled student as a player. A small change in orientation of the head becomes a preference for recess outside instead of inside. A sound a student might commonly make becomes that student's choice of one answer over another.

While these teachers may not "really know" what the student means or prefers, or even whether there was any intentional behavior at all, the ability to offer a construction that is commonplace and incorporative makes it possible for others in the setting to do so as well. Ethan didn't "really know" how to answer the question, but because Nora and Rick could explain how his confusion was similar to that experienced by any member of an audience trying to appreciate a character, others in the drama class were able to move on to creating more and more elaborate accounts of Ethan's membership in beginning drama. Nora, a friend of Ethan's for several years, had arrived at her account of his repetitive speech not so much as a professional but as someone trying to help him answer the person serving drinks at the concert or the waiter at the yuppie burger restaurant. By sharing her own strategy for making Ethan fit into her personal life, she created the opportunity for others to do so as well. Sometimes it is the *telling* of our own membership stories that holds the most power. So let me conclude with one more brief story about Ethan and his experiences in beginning drama.

As part of the end-of-year closure festivities and performances, Rick invited the class to select from among their number the male and female student who not only "showed the most improvement" but also "showed the most promise as an actor." Recounting the vote to me after the fact, Nora and Rick reported that they were surprised and moved to discover Ethan received seven votes. "If it had only been improvement, I could see it," Nora explained. "Ethan really did learn a lot that everyone could see."

"But promise as an actor!" Rick continued their thought. "That shows how much they came to value Ethan as a *member* of the drama class."

## Membership Activities and Resources

Membership may seem like a difficult concept. It certainly doesn't seem as easily measurable, predictable, or controllable as so many other, more familiar educational concepts. Fortunately, the very complexity of membership is the source of its value for us. Membership is not so much an educational concept as it is a community concept. All of us quite naturally know what membership means. We have all felt the sense of belonging that is membership's hallmark. The following activities and resources may help you translate your own natural familiarity



with membership into situations that involve children and youth with severe disabilities.

Activity 1: Take a wide-angle snapshot. On a regular basis, try to stand back and look at the whole setting as if you were an observer from another world. Try to notice the following about the person you are interested in supporting to be more of a member:

- 1. Where is the person in this space? On the edges? In the middle? In a cluster of others? More or less alone?
- 2. How does the person operate in this space? Does she move about this place more or less like the others? If not, how does she look in the pattern of ty? Does everything seem to pass her by or flow around her in a way that seems oblivious to her lack of movement? Or does she seem to deflect others by her activity?
- 3. How does this person look in this space? Are his differences minimized? Is he accessible to others? Does his equipment invite or discourage others from approaching and getting near? Do others approach this individual and his "stuff?" Do others seem to shy away? When? Why do you think?
- 4. What does the person do in this place? Does she do similar or different things? With similar or different materials? Do any differences seem to make others act differently with her?
- 5. With whom does this person do things in this space? Does he seem to have the same range and variety of interactions as the others like him in this place? Do adults or official people seem to interact with him more or less than with

the others? Do adults or official people interact with him differently or similarly to how they interact with the others? Do the other people like him in this place interact with him similarly or differently from how they interact with each other?

Now look carefully at your wideangle snapshot. Is there anything about this picture that makes you feel like this person belongs? What things give you that impression? How might you make sure that these things are always happening? How can you organize your teaching and support so that these things are not disturbed?

Is there anything about this picture that makes you feel like this person doesn't really belong? What things give you that impression? What could you change about the picture that might change your impression? Try it and see what happens.

Activity 2: Make up stories. On a regular basis, step back and listen like a storyteller in search of material. Watch the person you are interested in supporting and all the others around that person for how they are making each other commonplace in this place. Watch all the little subtle ways everyone talks, moves, gestures, looks, and fails to do these same things, then try to make up stories about the following. Remember that different people may have different stories. Try to capture them all for your repertoire.

- 1. Who do they think the person is? Is he just another one of us? Or someone else? Who?
- 2. Do they think she is younger or older than they are?



- 3. Do they think he "speaks a foreign language" or doesn't communicate at all?
- 4. How do they think she thinks? Like them? Differently? How differently? Only about some things but never about others? Does she notice the same kinds of things they do?
- 5. How do they think he feels about things? Does he think the same things and people are important? Silly? Does he get sad, happy, and mad about the same things? Different things? What different things?
- 6. What do they think she wants? The same things they do? Different things? What different things?
- 7. What do they think about the things he does or does not do? Are these things "weird" or intriguing? Funny or gross? Okay enough to hardly be noticed?
- 8. What do they think about the people and things that come with her? Do they notice these extra people and things? How do they explain why she has these people and things?

Now think about all the stories you have collected. Which stories seem to be about making the individual with disabilities belong? Which stories seem to make the person's differences commonplace? How? Are there stories that seem to be making the person a member in a way that seems unreasonably different or special? Are there stories that seem to be rejecting this person as a member?

Activity 3: Tell stories. Whenever you are with the person you are trying to support as a member, keep part of your mind focused on all the things you know from the wide-angle snapshot and the

stories you have been making up. As you decide how to interact with, teach, or help the people in this place, filter your decisions and actions through that layer of your thinking that is holding the snapshot and stories.

Make your actions and words tell stories of belonging by:

- using the stories of belonging already present in the minds of others in this place;
- reframing others' less incorporative stories:
- framing your "special" actions and words in ways that fit the others' belonging stories;
- emphasizing the ways in which the person is thinking about things;
- revealing how the person feels about things;
- letting others know what the person likes and doesn't like; and/or
- suggesting lots of different ways the person has a role in this place.

Activity 4: Read stories. Try to regularly read things that help you practice seeing the experience of being different from the point of view of those who directly experience it. Their own interpretation of the stories that others' actions and words tell can help you reflect on the messages your own words and actions might give.

The resources listed immediately following the references are just a beginning list. Use these to find others and share them with your colleagues and friends.

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