ALTERNATIVELY SPEAKING
JUNE 1994
VOL. 1, NO. 2

Literacy: The Key To Freedom

Parents of children with multiple disabilities often ask me how I have become so successful given the fact that I have a severe disability, use a wheelchair and speak unclearly. I usually answer this inquiry with one word: literacy.

The Power of Literacy

Literacy is a very powerful tool. It is a master tool from which all other of life's tools can be made. It is absolutely vital that every person who is unable to speak become as literate as possible. Perhaps your speech is unclear but you have someone who can understand it and can tell other people what you are saying. Things are fine as long as that person is around, but what if he isn't available to interpret for you or strongly disagrees with what you are saying and won't translate your words? Then what will you do? Without an alternative means of communication, you lose your identity as a human being. If you can write, you have a way to tell people exactly what you are thinking and feeling. If you can read you can recognize letters or words and construct messages on any display all by yourself. In short, life becomes more self-directed, easier and a lot more pleasant if you are literate.

What is Literacy Anyway?

The people I interviewed for this article had differing opinions about what literacy is. People who work in strict academic settings tended to define the area quite narrowly: To them literacy meant proficiency in reading and writing. Others defined literacy broadly and included such things as being able to recognize and understand logos. All my sources agreed literacy is a continuum that includes reading, writing, talking, listening and thinking. They agreed on another point, too: Everyone—young and old and particularly those who use AAC—can benefit from some kind of literacy instruction.

Although much of what follows talks about children, the information can be applied to adults, especially people with significant speech and physical impairments (SSPI) and developmental disabilities. It is extremely important to remember that literacy can emerge at any age. (And any amount of literacy is helpful.) It is never too late to learn reading and writing skills.

A Volatile Subject

Literacy has always been a hot field of research. I remember my introduction to this volatile subject came in the mid-fifties with the appearance of *Why Johnny Can't Read*, a tract–like manifesto that decried the lack of phonics—a method of learning words by sounding them out—in the public schools. Fierce debates broke out over the dinner table and in public arenas. Friends were lost because they were on opposing

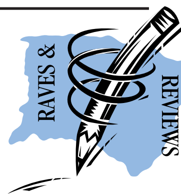
Continued on page 2

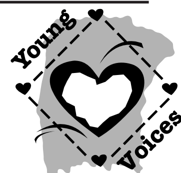
INSIDE THIS ISSUE

Literacy: The Key To Freedom

Literacy Support in the Home

Going to the Library

Dr. K and Mr. Hyde


Why Should People Learn To Read?


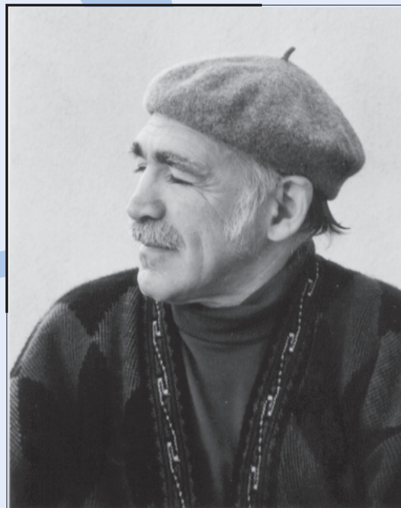
Message from the author

It always starts in the blackness of nothing. Then there is the light. It's dim at first, but it slowly grows brighter and brighter until I am almost forced to close my eyes. But still there is nothing—no thing out here in the hot white brightness that surrounds me to infinity. I try to move but can't. I'm tied to a chair. I want to call out to somebody, but who would hear me? I do anyway, but there's no answer. I try waiting but nothing happens. I run the gamut of my emotions, from hysterical laughter to stark fear and back again. It doesn't do me any good. I'm still here in this bright nothingness and then, for the first time in my life, I grasp the meaning of forever.

Then I wake up and find myself in safe harbor surrounded by the familiar things of my life. Let me tell you what I think it means.

I've always suffered from Dickens' Syndrome. This is the fear of being put in a large institution and having to stay there for the rest of your life. Your every move is controlled by the people who run the place. You are told when to wake up and when to go to bed. As far as food goes, of course they feed you, but you have little say over what you want to eat. Leisure time? There's plenty of it, but there's nothing to do. A few old books are over there on a shelf in a corner, but you've read them all and new ones won't be arriving any time soon. The television's always on but never turned to something you want to watch. It's like this year after year—nothing to do—forever.

This was a distinct possibility when I was in my teenage years. I was well aware of it; it lurked in the back of my mind like a grim specter. I was determined to avoid such a fate as this. I armed myself with the only weapon I knew how to use: high octane literacy. I discovered I could win friends and influence people by the power of the written word. The pen is indeed mightier than the eye. AS



Alternatively Speaking (ISSN 1075-3982) is published quarterly.
Copyright 1994 by Augmentative Communication, Inc.
1 Surf Way, Suite 215, Monterey, CA 93940. Reproduce only with written consent.
Telephone: (408) 649-3050. FAX: (408) 646-5428.

Author: Michael B. Williams   Technical Editor: Carole Krezman

One Year Subscriptions:
By personal check U.S. & Canada=$30 U.S.; Overseas=$38 U.S.;
Institutions: U.S. & Canada=$46 U.S.; Overseas=$54 U.S.
Single Issues $12. Special rates for consumers and full-time students.

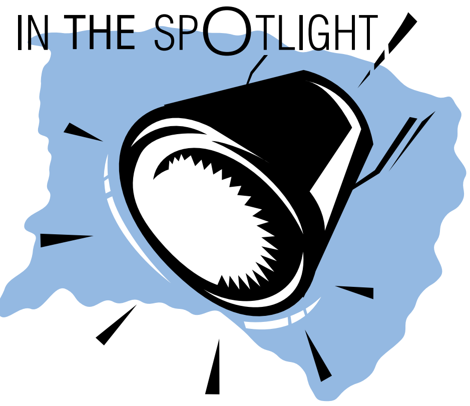
Literacy: The Key To Freedom

Continued from page 1

sides of the debate, and elections were won on the candidates' beliefs in phonics.

The ardor of public discourse has cooled considerably in the intervening years, but literacy remains a critical issue in most countries. Public interest in the subject is aroused from time to time as public figures champion the cause of literacy.

Meanwhile researchers have continued to do their work. There is a mountain of research on literacy. But look for research on literacy and people with SSPI, and all you will find is a molehill of material. Until the start of this decade, almost nobody was looking into this area of research. Regrettably this has occurred partly because of two widely held beliefs. One is the notion that success in literacy hinges on a set of pre-literacy skills (such as knowing the primary colors, the letters of the alphabet and having the ability to tract from left to right) that must be learned in sequence. Since children with SSPI often do not gain these pre-literacy skills until later in life, and sometimes never gain these skills, some educators consider it a waste of time to instruct them in reading and writing. The other notion is the belief among some professionals that good speaking skills and the ability to sound out words are prerequisites to reading instruction. Such ideas should be declared false on their face. I have



a clarity of speech equal to mud on glass, yet I learned to read at an early age. Some of my friends shared the same boat of early childhood experiences, yet they are able to read and write. If my teachers and therapists had accepted such restrictive concepts of literacy instruction, you probably wouldn't be reading this newsletter today.

Emergent Literacy

Educators have a much broader view of literacy than they used to. Instead of "reading readiness" with its ridged steps that must be done in sequence, researchers now consider something they call "emergent literacy". Emergent literacy takes a much broader view of a person's interest in text. It looks at both reading and writing, viewing those scribbles on a page a toddler makes and his nonsensical vocalizations as he turns the pages of a book as part of a continuum of literacy abilities. The developmentally disabled adult is pleased when she learns how to hold a magazine right side up. Now she can "read" with her friends.

Where does preliteracy stop and literacy begin? Researchers now consider this a useless question. Preliteracy and literacy are intertwined. Any attempt to separate the two is an impossible task.

What Researchers Know

Emergent literacy in children. Listening, speaking, reading and writing skills are interrelated and develop at the same time rather than one after another. Children learn about text structure and concepts of written language by listening to stories. Typical story phrases—"Once upon a time..." and "They lived happily ever after"—often show up in children's speech. Children frequently talk to themselves as they scribble, draw or attempt to write. When children begin to write words, they rely on what they think are the sounds of letters to invent their spellings.

Meaningful contexts. Literacy is best developed within a meaningful context. Children aren't born with an innate urge to read and write, nor do they know why it is important to acquire these skills. Children need to observe people doing every day reading and writing. Even the most mundane tasks such as reading the directions on a TV dinner or paying bills can serve as rich examples of why text is meaningful. Adults who don't read or write may become interested in learning when the see the utility and power of grocery lists or logo identification.

Literacy learning is a process of activity, construction and interaction. Early on, the facilitators of this are usually the parents. They engage children in story text by asking the child questions, such as, "Why did he do that?" and "What's this?" Such queries help draw a child's attention to the text and engage her in thinking about it. Children gradually learn to transfer knowledge from one text to the next. When they pretend to read their favorite books, they don't just rely on their memories. They often substitute words for those in the text, and these "mistakes" are often logical and synonymous with the genuine words.

Literacy and Developmental Disabilities. It should come as no surprise that most research indicates that persons with developmental disabilities have vastly different literacy experiences than do their nondisabled counterparts.[1] The reasons for these differences are many and varied. Physical, sensory or communicative difficulties may make it hard for a person to explore printed materials on his own. These factors may also hinder interactions about text with other people. Children with developmental disabilities are often exposed to literacy at a much later age than their peers. Research shows that many children with Downs syndrome don't come in contact with print materials until the age of eight or nine.[2] Research has also shown that people with SSPI often don't write because they lack access to writing tools or opportunities to use them.[3]

Low Expectations. Research also indicates that parents and teachers have lowered expectations of children with SSPI when it comes to literacy. This was demonstrated in a survey of literacy expectations by Light, Koppenhaver, Lee and Riffle.[4] In another survey parents of children with SSPI ranked achievement in literacy lower in importance than did

Continued on page 4

Continued from page 3

parents of nondisabled children. The parents of SSPI children were more interested in their child's face-to-face communication and self-help skills rather than literary skills.[5] The lives of people with SSPI are usually filled with activities other than reading, writing and other pursuits of an academic nature. Harried parents of SSPI children often feel overwhelmed by the daily tasks of life. Such basics as bathing, toileting, dressing, feeding and keeping up with the endless stream of doctor and therapy appointments leave little time for anything else. The lives of adults with SSPI can be equally full of survival activities. Just getting through the day can be an exhausting and daunting task. Reading and writing often get shunted to the side in favor of the main goal: managing one's survival.

What Works

What has made a difference in the literacy of adults with SSPI? Koppenhaver, Evans and Yoder surveyed a group of literate adults with SSPI between the ages of 16 and 55 years.[6] Results of this survey indicated that all of the respondents had grown up in print–rich environments. All were read to at home, and most received direct instruction in literacy at school through the sixth grade.

However, I count among my friends people who never had these advantages and are learning to read and write as adults. It's never too late to improve one's literacy.

Partners Toward Literacy

What can you do to help a person with her literacy? The people I talked to while working on this article agreed on one thing: Literacy opportunities are literally everywhere.[7] Reading should not be restricted to ritualized story book sessions,nor writing to the classroom. Below are just some of the literacy activities you can do.

- Use the daily mail. It brings lots of opportunities. Junk mail often has nice big print with bright pictures, perfect for pointing out a word or two.
- Discuss something each day from the newspaper.
- Utilize the billboards that seem to lurk around every corner the next time you are driving down the road to another boring therapy appointment.
- Make sure your literacy partner can see the recipe you are working on during meal preparation. Point out the word of each ingredient.Talk about each step.
- Make grocery lists. Perhaps your literacy partner can participate in writing the lists.

Let your imagination run wild. Be creative. Above all be enthusiastic about what you are doing. Your enthusiasm will be contagious. AS

Want to know more about literacy and disability? The Center for Literacy and Disability Studies is doing seminal research in this field. To get a brochure about the Center's activities and a list of its publications, write or call:

The Center for Literacy and Disability Studies, University of North Carolina at Chapel Hill, 730 Airport Road, Suite 200, CB#8135, Chapel Hill, NC 27599-8135, (919) 966-7486

Lite

We all want our children to learn to read and write as best they can, and with any luck, to enjoy their literacy. Ensuring this outcome can be a daunting project for parents and guardians of children with disabilities.

I talked to two parents, Judith and Fran, in order to get some specific hints about helping your child become more literate.

High expectations for their children's success in literacy: This may be the most important factor.

Judith and Fran have children with cerebral palsy who use communication devices. Judith has a twelve year old daughter, Ana. Fran rears her twelve year old grandson, Chris. Both are tenacious advocates for their children, and both realize how important literacy is for people with significant disabilities. They have high expectations for their children's success in literacy: This may be the most important factor. They *believe*, and Ana and Chris know it.

Ana's Story

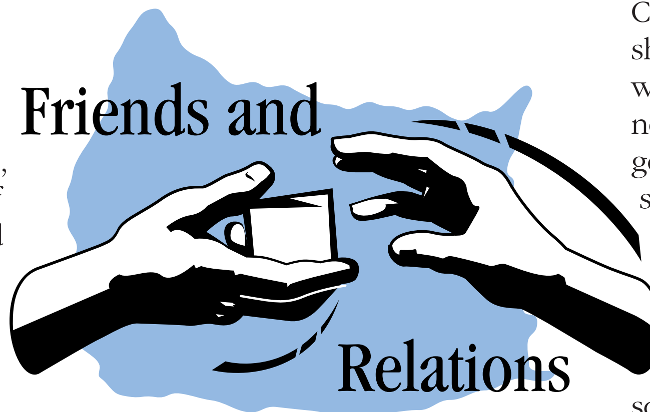
Ana began reading early. I recently asked Judith when she knew Ana could read. She told me an interesting story: Ana and her family were flying back to California from the East coast. To break up the tedium of the long flight, Judith decided to play a game with her daughter. The

eracy Support in the Home

names of items on Ana's communication board were written under their respective pictures. Judith was interested in seeing if Ana had soaked up any of this information. Judith wrote "Mom" on an erasable slate and asked Ana if that word was on her communication board. Ana pointed out "Mom." Then she wrote "Dad." Again Ana could match the word with the picture on her communication board. By the time Ana recognized her sister's name, Judith was convinced Ana was beginning to read. She was three years old at the time.

Ana's family has paid close attention to the development of her literacy. From the time she was very small, Ana has heard the sound of language being spoken and read in her home. Besides immersion in a language–rich environment, Ana has also had literacy instruction at home. From Ana's infancy, Judith would sit on the floor behind Ana with Ana between her legs, and a low table in front of them. This was Ana's "office." Here they would play with homemade flashcards learning the basics of phonics and sight-reading. They would sing and read. They also went out in the community to enjoy books, songs and stories with other young children at library "lap–sit" children's reading programs. As a result, Ana was reading quite well when she started school in a regular education kindergarten.

This preparation served Ana until she reached fifth grade. Reading gradually became a problem. Her ability to read was not improving as quickly as her classmates. Decreasing type size and difficulty handling books are suspected to be the main problems. Ana's parents and education team are coming up with strategies which they hope will be as successful as Judith's early efforts. They have decided to scan Ana's books into her computer so she can read them in what ever size type is comfortable for her without any page turning problems.



Chris' Story

Fran and her grandson Chris have had a quite different experience with literacy. Reading and writing have been difficult for Chris. He and his grandmother have had to play catch–up because Chris was allowed to do basically nothing for the first six years of his life. Then he attended a special education class an hour and a half from his home. The children in that class were all much younger than Chris and only one was verbal. This did nothing to improve his literacy.

Now Chris is in a sixth grade inclusion classroom in his neighborhood school. Unfortunately Chris' teacher and aide know little about computers and don't have the support they need to hook Chris' communication device up to his classroom computer. As a result Chris is unable to participate in class writing assignments.

Needless to say, this has not been a scenario for success in literacy. Fran is trying to make up for lost time and for the lack of support at school. She knows how important it is to read to Chris. When she reads to him, she tries to select books which will teach him something he needs to know in social studies, geography, history or other class subjects.

Chris has good writing tools at home—a computer he can easily access and lots of writing and literacy oriented software. So far he is not too enthused, but Fran continues searching for ways to motivate Chris in writing activities. She isn't giving up on her grandson.

Both these parents have shown great dedication in their efforts to bring literacy to their children. They know that the path to literacy is filled with many frustrations. They continue on the path in spite of everything, because they know not to do so will bring even greater frustration and hardship to their children later on in life. AS

Going to the Library

I am an inveterate reader. I stumble out of bed in the morning and roll up to the kitchen table where I fuel my lethargic system with a cup of strong coffee and engage my fuzzy brain with the morning newspaper. No chirpy morning TV shows for me, thank you. I'd rather gently massage my mind awake by reading a few of my favorite columnists as they punch away at their latest straw men.

I read throughout the day, whether it be electronic mail on my computer, research articles or the latest effort from my favorite mystery writer, Walter Mosley. I can't seem to tear myself away from the printed page.

And what do I do for fun? I go to the library. No snickering in the peanut gallery. I know some of you think a trip to the library is a torture dreamed up by teachers, especially when there's homework involved. For me, however, going to the library can be a pleasant way to spend a few hours on a lazy weekend afternoon. I practically have the place to myself. While other people are waiting in line for the latest Hollywood product, I am prowling the depths of my local library hoping to unearth a buried literary gem. More often than not I am successful.

There is much more to a library than books these days. Your friendly book lender may have books on tape in addition to music and videos. Books on tape have really been improved during recent years. Fueled by the popularity of portable tape players, publishers have been issuing audio versions of popular texts soon after the books come out. While the taped versions are most often abridgments of the original texts, they are usually skillfully done and read with just the right tone and feeling by a notable personality.

If you haven't been in a library in a while, get ready for a change. Libraries are getting rid of their card catalogs and replacing them with on–line computer terminals. This is great news for those of us who use wheelchairs. In the days of card catalogs I had to bring somebody along to help me look things up. I could never reach all the drawers of the card catalog, some were too high, others were too low. If I could reach a drawer, I was then faced with the daunting task of flipping through all those little cards just to see if the library had the books I was looking for. It was a most tedious and frustrating experience, not just for me but for other library patrons as well. Not only did they have to wait while I searched slowly through my drawer, but my wheelchair would block a lot of the other drawers too. Did I ever feel the pressure of all those eyes staring at me! I often left before I was finished.

Well all that has changed. If I'm feeling lazy and have a particular book I want in mind, I type a note to the librarian and have him search it out for me. When I go to the library to do research, I pull up to a computer terminal that is at about the right height for my wheelchair and start typing.

When you are searching for a book in an on–line card catalog, you can look for it by the traditional methods of the author's name, the title of the book or the subject of the book. The on–line card catalog also lets you look up a book by typing important words from the title. The other day I was looking for a children's book called *The Five Hundred Hats of Bartholomew Cubbins* by Dr. Seuss. I wasn't sure how to spell the author's name or the name of the book's hero, so I typed the words "five hundred hats" into the computer. In a few seconds I had all kinds of information about the book on the screen.

Some libraries let you call their on–line card catalog from home via your computer and modem. No more worrying about people waiting in line for the computer terminal while you are trying to look up a book. You can even see if anyone has checked out the book you want before making the trek to the library.

If you haven't visited the library in a while, check it out. You may find it has lots of things you are interested in. AS

Dr. K. and Mr. Hyde

Ordinarily I'm not a masochist: If a family conflict arises, I run and hide under the bed; if a grim headline intrudes upon my morning coffee, I quickly find the sports page or comics; if things get rancorous on a radio talk show, I quickly switch to lite rock. In short, I would never make it as a diplomat or labor negotiator.

It was with some trepidation, then, that I started watching the trial of Michigan vs. Kevorkian. The defendant in this case was Jack Kevorkian, a medical doctor who passionately believes in the right of people to terminate their lives when faced with endless suffering. The good doctor also believes that people should be able to get help in this task from a physician.

Doctor Kevorkian was charged in this case with violating Michigan's assisted suicide law by causing the death of Thomas Hyde, a young man with amyotrophic lateral sclerosis (ALS). Kevorkian provided Hyde with a lethal quantity of carbon monoxide. The doctor claimed his sole purpose in doing so was to relieve Hyde's pain and suffering. Kevorkian's lawyer used this line of reasoning, along with a more technical argument about where the deed was actually committed, to convince the jury of the doctor's innocence.

Soon after the jury's verdict, Doctor Kevorkian was on prime time nation–wide television proclaiming his intention to carry his fight for physician–assisted suicide throughout the land. The good doctor proceeded to give examples of who might wish to terminate their time on earth. Among the usual terminally ill folks he trots out for such occasions, he included a man who is paralyzed from the neck down. Kevorkian looked straight into the camera and incredulously told his audience that this guy could live another twenty to thirty years in this condition. What the doctor means, of course, is nobody in their right mind would even want to consider living a life in this condition.

This is what I find so odious about Dr. K. and his ideas on physician–assisted suicide. He always sees the glass of life as half empty rather than half full.

Indeed, this is what I find so odious about Doctor K. and his ideas on physician–assisted suicide. He always sees the glass of life as half empty rather than half full. This came up time after time during his trial. His lawyer kept hammering away at how disabled Thomas Hyde was and how horrible his prognosis would have been had he lived. He kept pointing out what Thomas Hyde couldn't do, like feed and bathe himself. Near the end of his emotional closing argument Jack Kevorkian's lawyer held up two photos of Thomas Hyde in a before and after comparison. Those of us who were watching the proceedings on TV couldn't see the photos, but Kevorkian's lawyer left no doubt as to what he was up to. The photo in his left hand was Thomas Hyde before he got ALS. He slowly held his right hand out; he looked intensely at the jury and called the image in his right hand a "monster" who couldn't hold his own child.

At this point I wanted to jump through my television set and silence this glib–mouthed officer of the court. He was, in contemporary parlance, talking trash—the worst possible kind of trash. He not only denigrated the memory of Thomas Hyde, he insulted every seriously disabled person in America.

I am not a monster. I am a fighter. I am engaged in a more than five decade struggle with a body that refuses to do the most basic of tasks. Each day we battle to a draw. I have been helped along the way by a community of friends who believes that having a disability need not consign you to the trash heap of life. From what I have been able to glean from the media, Thomas Hyde never had a chance to see the glass was half full rather than half empty. AS

Literacy is reading, writing and thinking. Being able to read, write and think has been very important to me all my life. It helps me get what I want and need. It helps me have fun. I asked my friend Fran from the Chicago, Illinois area to find out what children there think about literacy. The question I asked was,

"Why should people learn to read?"

"Reading is good because you can learn a lot of things in books." **Ryan, age 11.**

"To learn words. To get smart." **Chris, age 12.**

"So I can read the sports page to see if the Bulls have won." **Barry, age 15.**

"When I was eight I had strokes that took my ability to read for myself. Because of that, I discovered reading is important. Reading can take me places and show me things I'll never be able to see because of my strokes. It lets me use my imagination to meet people like Harriet Tubman, the Presidents, Noah, Ben Franklin and Jackie Robinson, to know what they did and how they felt. Reading lets me help Frank and Joe Hardy solve mystery after mystery. It shows me how people live in different places and times. The strokes took my sight, my voice and my sense of touch, but not my sense of imagination. Reading helps me to use it to make my life better." **Ben, age 12.**

I want to know what kinds of work you want to do when you are older. Tell me your answer to this question

What do you want to be when you grow up?

You can write to me: Michael Williams, Augmentative Communication Inc., One Surf Way, Suite 215, Monterey, California 93940. You can send me a fax at (408) 646–5428. Or you can send me electronic mail at mbwill@well.sf.ca.us

Thanks to Frances Featherly for her assistance.

Sources & Resources

1. Koppenhaver, D., Pierce, P., Steelman, J., and Yoder, D. (In press). Contexts of early literacy intervention for children with developmental disabilities. In M. Fey, J. Windsor, and S. Warren (Eds.). *Language Intervention in the Early School Years.* Baltimore: Paul H. Brookes.

2. Koppenhaver, D., Coleman, P., Kalman, S., and Yoder,D. (1991). The implications of emergent literacy research for children with developmental disabilities. *American Journal of Speech-Language Pathology: A Journal of Clinical Practice, 1* (1) 38-44.

3, 6. Koppenhaver, D., Evans, D., and Yoder, D. (1991). Childhood reading and writing experiences of literate adults with severe speech and motor impaiments. *Augmentative and Alternative Communication*, 7, 20-33.

4. Light, J., Koppenhaver, D., Lee, E., and Riffle, L. (1992). *The home and school literacy experiences of students who use AAC systems*. Unpublished manuscript.

5. Light, J. and Kelford Smith, A. (1993). Home literacy experiences of preschoolers who use AAC systems and of their nondisabled peers. *Augmentative and Alternative Communication*, 9, 10-25.

7. Locke, Peggy. (May, 1994). Personal Communication.

Janice Light. Penn State Univ., Dept. of Communication. Disorders, 217 Moore Building., University Park, PA 16802.

Peggy Locke. Ablenet Inc., 1081 Tenth Avenue S.E., Minneapolis, MN 55414.

Caroline Musselwhite. 916 West Castillo Drive, Litchfield Park, AZ 85340.