

Proceedings

of the

Biennial

Pittsburgh Employment Conference
for Augmented Communicators

PEC@ '03

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Editors
Robert V. Conti
Thomas J. McGrath III

Graphics
Mark A. Zucco

Conference Chair
Bruce R. Baker

Conference Coordinators
Carolyn Micher
Steve Schmidt
Linda Boeltz
Steve Osgood

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PREFACE

Biennial Pittsburgh Employment Conference for Augmented Communicators PEC@ '03

Partners and Strategies in Employment for Augmented Communicators

SHOUT is pleased to be sponsoring the Biennial Pittsburgh Employment Conference for Augmented Communicators. This year's topic: Partners and Strategies in Employment for Augmented Communicators, are issues at the heart of adult life for people who could rely on augmentative communication systems.

Welcome to this year's Conference.

Bruce R. Baker
PEC@ '03 Chairperson

Table of Contents

PREFACE

ii

Partners and Strategies in Employment for Augmented Communicators
Bruce Baker, *A.M.*

PLATFORM PRESENTATION

v

1 Jennifer Lowe, Executive Director, SHOUT

1

XXX

3... Skills, Equipment and Preparation: Essential Elements for Employment

3...

Richard D. Creech, M.S.

Going for the Gold: Why I Chose to Study Law

Fiona Given, Esq.

Going to College as a Strategy for Employment

Beth Anne Luciani (Chairperson)

William Adams
Robert O’Gurek
Sarah Lever

Want to Work – Get a Voice: AAC Funding Update

Lewis Golinker, Esq.

Vocabulary Augmented Communicators Actually Use On The Job

Katya Hill, Ph.D.

David Chapple, B.S.

Starting Your Own Business

Victor Valentic

Dennis Hollman

James Prentice, B.A. (Chairperson)

Snoopi Botten

ACETS Online: Electronic Job Coaching for AAC Users

Kevin J. Cohen, M.S., CCC-SLP

Diane N. Bryen, Ph.D.

Ami Profeta

My 15 Minutes of Fame: Winning an Academy Award for “King Gimp”

Dan Keplinger

Full-Time Professional Employment:

Working for the U.S. Naval Center

CONTACT_Con-466ACC3F2C \c \s \l Solomon Rakhman, B.S.

Road to Success: Working for a Major Insurance Company

James Protho, M.S.

**The Experiences of Undergraduate Students Who Were Taught by
Lecturers Who Use AAC**

David Trembath, B.A. app.sci (Speech Pathology)

The Importance of Starting AAC Early

Irene Hohn

Getting a Job – The Nuts and Bolts, A Conversation

Kevin Williams, B.S.

Randy Kitch, B.S.

Making It: A Ph.D., A Wife, and a Job

Bob Segalman, Ph.D.

Working in Marketing and Public Relations for AAC Companies

Rick Hohn

Anthony Robertson

David Morris, B.Ling, M.A., DipCCS, MRCSLT

Obtaining Funding for a Major Project

Jon Feucht

Jennifer Lowe, B.A.

Anthony Robertson

AAC and Cell Phone Usage: An Off-the-Shelf Solution

Diane N. Bryen, Ph.D

Paul Pecunas

Opening Up a "Whole New World": Employer and Co-Worker Perspectives on Working with Individuals who use Augmentative and Alternative Communication

David McNaughton, Ph.D, David Chapple, B.S., Janice Light, Ph.D.,
Stephanie Gulla, M.S., CCC-SLP

Town Meeting—Topic: Strategies and Partners in Employment

Speaker of the House: Randy Kitch, B.S.

Marriage and Employment: Domestic Life

Randy & Brenda Kitch

Kim Vuong

Anthony Robertson

Randy & Kimberly Horton

Kate May & Juan Gonzalez

Rick & Irene Hohn

Working in Technical Service and Training for a Computer Company

Anthony Arnold

Jane Burgan

David Chapple, B.S.

Bac Shelton, B.A.

Preview of the University of Dortmund Project

Andreas Seiler-Kesselheim

Working in Politics

Ryan Duncanwood

Tiffany Adams

Randy Horton

Unexpected Uses of AAC Technology for Employment

Sue Rubin & Rita Rubin

Being an AAC Advocate

Bac Shelton (Panel Chair)

Leigh Ann Lightholder

Donald Jones, B.S.

Ray Peloquin

Paul Garrick

Sara Pyszka

Kyle Glozier

RERC Projects Benefit the AAC User:

Communication Disability Employment and Social Networks

Blyden Potts, M.A., Allison Carey, Ph.D., CONTACT _Con-466ACC3FF3 \c \s \l

Diane Bryen, Ph.D.,

Kevin Cohen, M.S., CCC-SLP

Tell Me About It: Communication At Work

Susan Balandin, Ph.D.

AUTHOR INDEX

71

PEC@ 2003
Platform Presentations
Strategies For Employment

Augmented communicators need to have independent living skills on any job. We must be able to act as an independent agent. We need to organize ourselves so that we need minimum assistance and guidance. This carries into our private lives too. I am not ashamed to ask anyone's help when I need it, but we should be ashamed to ask for help when we shouldn't need help; when we should have been able to learn how to do the thing ourselves.

To perform well in competitive employment, we must do what it is possible for us to do as independently as possible, and graciously accept help with things we cannot do. And even more gracefully decline help from someone who is absolutely certain that we need help, even when we don't need, don't want, and don't much appreciate the help.

Richard Creech, Skills, Equipment, and Preparation: Essential Elements for Employment
Proceedings, PEC@ '03, page ???

Partners for Employment

Being a computer programmer for Highmark is the job I have always wanted. In October it will be two years I have worked there. In that time I have worked on a few different areas. I was on the HIPAA project, which stands for Health Insurance Portability and Accountability Act. This act requires that the companies that have Highmark as their health plan be the same format. When I first started, I worked on the benefit enrollment and maintenance. Recently, I worked on referrals and authorizations. A while ago, my team was informed that our project was coming to an end. So we all had to find other positions. Fortunately, I found another position. I now work for the General Ledger Systems. Because programming jobs requires quality not quantity, I am able to meet deadlines. The time we are given to complete programs is more than enough time. I have not needed to ask for more time. The money I earn is more than enough to take care of the bills I have. I work seventy-five hours every two weeks making between \$30,000 and \$40,000 a year. The job at Highmark is the job I have always wanted.

James Protho, Road to Success: Working for a Major Insurance Company
Proceedings, PEC@ '03, page ???

Partners and Strategies for Employment

... I have had several jobs and being a professional in the disability field, or any work field, is more than just making a good salary. Personally, I feel we must enjoy our jobs and be happy doing them. If we aren't, then it is time to move on. Although, there are times you need to stay put and attempt to readjust your mindset on how you feel about your work. This would give you time to look into finding another job to graduate into. Being a professional also means taking responsibility, asking questions, being on time for work and meetings, supporting your co-workers and vice versa. Above all, being a

professional means working together with others as a team. Thus, I have decided to change my definition of a professional to... “Someone with expert skills in a certain area or areas.” Sure, a good salary helps... but you do not need to be a paid employee to be a knowledgeable and teaching person. If you are able to share even in a voluntary capacity, it could turn into paid work there or somewhere else.

Randy Kitch, Working As A Professional In The Disability Field
Proceedings, PEC@ '03, page ???

Skills, Equipment, and Preparation: Essential Elements for Employment

Richard D. Creech

For augmented communicators to work a job, we must have the skills needed for the job; equipment, very often beyond what someone else would require for the job, and we must be prepared to work the job.

Of course, the level of skills an augmented communicator needs to work a job depends on the job, but invariably the augmented communicator's skills will have to be, at least, two times greater than what the job requires. You can bemoan this, but that won't change the situation. Employers view augmented communicators as high-risk employees. To get around that perception, we must offer something so good that they cannot refuse.

Most jobs require a certain level of education. Generally, the more professional and higher the salary, the higher the education requirements for the position is the norm. We are not going to find a job paying forty thousand annually requiring only a high school diploma. We cannot be like my son who believed a company that told him, he could earn thirty, forty, an hour loading trucks. What they neglected to tell him was to earn that much, he would have to be the Hulk. We, as augmented communicators, have to realistically look at how much income we will need to live the life we would like, and look at the jobs that offer that income level; choose a few we would like; and then look at the education requirements; then start working towards obtaining the necessary education or training.

Augmented communicators need to have independent living skills on any job. We must be able to act as an independent agent. We need to organize ourselves so that we need minimum assistance and guidance. This carries into our private lives too. I am not ashamed to ask anyone's help when I need it, but we should be ashamed to ask for help when we shouldn't need help; when we should have been able to learn how to do the thing ourselves.

To perform well in competitive employment, we must do what it is possible for us to do as independently as possible, and graciously accept help with things we cannot do. And even more gracefully decline help from someone who is absolutely certain that we need help, even when we don't need, don't want, and don't much appreciate the help.

Augmented communicators have to be socially skillful. Not only must we communicate well, we must also be adept at other social graces. Unfortunately, that also includes political adeptness, which I am about as politically adroit as a one legged duck. However, working for a state funding department for ten years, I have learned to word my spoken

and written comments a bit more diplomatically; well, sometimes.

By social skills, I also mean how we treat people. My wife often accuses me of ignoring people, and I have to admit, it is one of my faults. When I don't really know a person, it is very difficult for me to be communicative with that person, and it is not that person's fault. It is really mine. Of course, it doesn't help if that person says something stupid like, "I'll bet you like that communication thing." But, at least, they are making an effort. I am just not good even after years, at what is termed "polite conversation." However, we should be. We need to be able to chitchat. It's a valuable social skill. Remember, work, is not just producing a product. Successful work includes networking, affecting a professional, but friendly demeanor, and being able to make people feel comfortable communicating with you. If you can do that, then you can do something extremely valuable, and extremely marketable.

Having the skills necessary for work for us is not sufficient. We need special equipment so that we can work. As augmented communicators, we need augmented communication systems. That's obvious.

However, for most of us, we have other disabilities, which require assistive technology to maximize our capabilities besides speech. For myself, I have my wheelchair, my van, my head-pointer, and my attendant, who is not technology, but sure is assistive, well, sometimes, when she is awake. Assistive technology has to be in place, I would say, before we look for jobs. Employers will not be impressed by what we say we can do when we have the assistive technology. We have to show employers what we can do having the assistive technology. We have to have and be damned proficient with the assistive technology we need before going to that interview. That's a bit like expecting a driving examiner to give you a license, after telling him, you have never driven a vehicle, but you scored a hundred on the written test. It isn't going to happen.

On a job, we will probably need other accommodations, which are not quite assistive technology, but adaptive. For instance, I have the light bulbs in one fixture removed, and the light from the other light fixture re-directed, so that it does not shine directly on my communication aid, the Pathfinder. I have tables and desks on blocks to make them higher. I have bulletin boards on my office's walls, because when I file papers in a drawer, they are effectively lost to me. I have a scanner to scan papers into my computer. Other than the servers, my computer has one of the largest hard drives at Pennsylvania Training and Technical Assistance Network (PaTTAN).

All this might not be called assistive technology. Lots of these are not even technology, but they are adaptive to my special needs, which I had to identify, and explain to my employer. Explaining things to employers requires very good communicative skills, even if the actual job does not. You're always going to need good communication skills.

One of my quotable sayings is, "Assistive technology without training, is not assistive." We cannot be given assistive technology we need to work, without training, and in three months, be expected to wow employers.

Some funding sources must think that people needing augmented communication are the smallest people on earth. That, or after funding a multi-thousand dollar device, they do not really care if the person uses it. Getting funding for training hours from some funding sources is like pulling a chicken's teeth.

We do have some good funding sources around. I will mention three with which I have experience. Private insurance. Believe it or not, I have been able to persuade my insurance to purchase a power chair and a Pathfinder with my famous second display, which I sneaked by my insurance. And I am presently negotiating with my insurance for a new wheelchair.

Negotiating is not quite the correct word to describe trying to get insurance companies to shell out money. "Disputing," maybe. My theory about insurance is that the first response will be a denial, and if you persist, they delay everything, hoping that you will die, before they will have to pay. I am serious. Every time I request some assistive technology for my insurance company, I think, God, I hope they don't have any hit men on their payroll, because dying would be the only way I am going to get off their backs.

The Office of Vocational Rehabilitation (OVR) is a great funding resource in Pennsylvania. I really have nothing bad to say about Pennsylvania's OVR. If your goal is employment, and if you are able to articulate what you want and if you know OVR rules, you can get what you need.

The third funding source that I personally have dealt is the Pennsylvania assistive technology loan program. They offer very low interest loans to people needing assistive technology. This is a great program for us. They don't buy assistive technology, but they loan you the money at very easy terms, so that you can buy the assistive technology. I have used this program, and I will be using them again.

Employers are funding sources; however, I have always been careful about what I ask them to purchase for me. I have asked my employer to purchase mostly adaptive stuff like bulletin boards, software, etc., stuff that they would not feel imposed on their budgets. We know that employers have to make reasonable accommodations, but the wise thing for us to do is learn to make necessary reasonable accommodations, no big thing to our employers. "Oh, you need this, to do that, no problem."

Okay, we have the skills, and we have the equipment, and we want to work. Next comes preparation to work. Getting the skills and equipment is preparing to be able to have a job. What I am speaking about now is preparation to go to a job, work at that job the number of required hours, and knowing what we are going to need to do the job.

Employers do not like surprises, and they do not like bumps in the road. We have to know what we are going to need to do the job the employer hires us to do, and be up front with the employer about what you are going to require. We also have to develop our support network for work, not only at work, but who is going to get our backs, as my sons say,

when we are in trouble. And ha haa, trouble is a way of life; you better plan for trouble, because trouble happens. We have to know what organizations are there for us, and we need to know, which persons in those organizations to contact, and, uhhummmm, which persons to avoid contacting. By the way, this goes for the work place also. Avoid, some, people!

Transportation never should be the employer's problem. You work out transportation. Employers do not want the headache of your transportation. Employers fire people with chronic transportation problems. Do what you have to do to ensure reliable transportation to and from the job. We have to work to solve problems before they become the employer's problems. That comes from knowing ourselves, knowing our capabilities, knowing our supports, and putting them all together to perform our job to our satisfaction. Work, a job, a career means different things to different people. For us, it is a hard won accomplishment that crowns our lives.

Going for the Gold: Why I Chose to Study Law

Fiona Given, Esq.

The year is 1986 and I am eight years old. I'm sitting in a classroom in a special school, located on Sydney's North Shore. We are having a discussion about the future. I am asked the question, what do you want to when I leave school? I ponder the question and respond, "I'm not quite sure what I want to do, but I'm not working in a sheltered workshop." People look at me rather strangely as though I was quite mad and proceeded to ask why not. I can't remember what my answer was.

In those days, at least in Australia, people with disabilities in open employment were unusual. For people with complex communication needs, it was totally unheard of. There were hardly any high tech AAC devices. I can remember seeing a device for the first time. I think only one boy at the school had a TouchTalker. I think his parents were very well off. I did not think I would ever have one. I did not envisage ever needing one either because most people one. Anyway here I am, using the Pathfinder.

I think the fact that communication devices were so rare, that it seemed impossible for people with complex communication needs to be employable. For some this situation has been rectified. Communication devices are more readily available. However, there are still big problems getting funding for them in my state, because our health department

does not consider them to be a high priority. I think this is outrageous. If a quadriplegic were not able to get a power wheelchair all hell would break loose. This is a reflection of the current state of the disability rights movement in Australia.

I don't know if it's the same in the United States, but in Australia, especially in my state, people who use AAC come near the bottom of the barrel.

This is a huge problem I face with absolutely everything, especially in terms of employment. I find the hardest people to win over are other people with disabilities. They just do not want us sitting at their table. Where I live the two peak lobby groups have a long history of being dominated by the paraplegic and quadriplegic movement. However, there are now three people with complex communication needs sitting on one of the peaks, including myself. This is very promising. I think they're finally starting to realize that we have something to offer. There are still battles to be won.

I have been looking the issue of citizenship and people with complex communication needs for a few years. I think we are behind the rest of the disability movement simply because it is harder to get ourselves heard. I was talking to an academic in my faculty about a research project I'm doing on the accessibility of the courts for people with complex communication needs, and he made a comment, which made everything suddenly make sense. He said not all disabilities are excluded from citizenship, but people with complex communication needs are. There is so much evidence that supports this claim.

In Australia there is only about half a dozen people with complex communication needs in open employment. I will only be the second lawyer in the country who has complex communication needs. The first was a lady called Maree Ireland. Her story is truly inspirational. She studied law after spending twenty years in a sheltered workshop. Maree was admitted as a solicitor last year. At the moment she is still working in disability but is looking to get a job practicing. So actually practicing as a lawyer with complex communication needs in Australia is unprecedented.

Law graduates with disabilities generally are finding it very difficult to find jobs. The law profession is still very old school minded. It is very much concerned about presentation and excellence. They want the best of the best. Law firms require graduates to have an excellent academic record as well as work experience and community involvement. This makes it extremely difficult about people with disabilities. The sheer effort of getting through a law degree is difficult enough without working at the same time. Furthermore many people with disabilities cannot perform the tasks, which are carried out by paralegals. In Australia we call them gopher type jobs because they involve activities like photocopying, filing, and getting lunches.

The NSW Young Lawyers, have recognized these issues and have set up a committee to try to address the problems of law graduates with disabilities gaining employment. The organization comprises of law students and lawyers up until the age of 36. The President, who is a friend of mine, is taking it very seriously. At the Mid-Year Assembly he invited three members who had Cerebral Palsy, including myself. A few of us think he did this

on purpose to make other members aware of the issue.

Overall the weekend was a success. I was impressed by the organization and its approach to people with disabilities. The thing that really strikes me about this organization is that they are proactive. They are starting to talk approaching disability organizations to form partnerships. We all know that it is often the other way round. Disability organizations approaching mainstream organizations.

We are just at the very beginning stages and we have a lot of issues to work through. Professionals with disabilities are not a common place in Australian society, especially professionals with complex communication needs. There is so much that is unknown.

The first major issue is fatigue and over use injuries. I have already starting experiencing those issues. Last year, I had carpal tunnel syndrome and had surgery on both hands. Now I'm starting to get pain in my elbow and shoulder. I think this is because I type to study as well as communication. This is a concern for when I start work because I'm not sure that I will be able to work full time. Another person I know who uses AAC and works also has problems with over use injuries.

This may shorten people's working lives. In Australia the average age for retirement is 65. We have superannuation schemes which people contribute to throughout their working life and this funds their retirement. If people with disabilities do have to retire early, and there has been anecdotal evidence that this is the case, it may mean we either have to make a greater contribution to their superannuation fund or have less money on retirement. The alternative is the possibility of a shortened lifespan, which would mean we might not reap as many benefits from our superannuation investment.

Another issue where I live is attendant care at work. Currently, there is no provision for receiving attendant care at work in open employment. However, this is going to change in 2005. Some people think it reflects poorly on the person with the disability if they receive attendant care in the workplace. I believe that the fact that I require assistance at mealtimes and in the bathroom does not have any impact on my ability to work. I currently do some work for Sue Balandin and she allows me to have extra time to fit in personal care. But obviously not every employer will be as understanding as she is.

Transport for people with disabilities in Sydney is a problem. The main form of accessible transport is taxi. We have some accessible buses and trains but they are not very secure. The Department of Transport provides us with half price vouchers but it is still expensive. I live about 20 minutes from the city and it would cost me about \$US 15 per day if I worked in the city. This is a major deterrent from working for many people with disabilities. In addition taxis are unreliable. Many people find they have to have a private driver in order to get places on time.

As you can see there are some major systematic and structural problems to get around. In terms of AAC, I feel I'm launching into the unknown. The Pathfinder and semantic compaction systems are virtual unheard of in New South Wales. That is why there is a

contingent of us at PEC. We are really keen to learn more and to see what it can do for people. I have had basically had to teach the system to myself. My therapists and attendants don't even understand it. They all go "that is Fiona's domain, it's too hard for us". I'm improving but I still resort to spelling mode a lot.

This lack of awareness may be a problem for employment and further study. Next year I have to do the College of Law. You would think six years of university was enough but apparently that is not the case. I will be required to sit written examinations at the conclusion of my time at college. I have no idea whether they will allow me to use my Pathfinder to complete the examinations because they might consider the use of Minspeak® as cheating. However, if I used a regular keyboard it would take me much more time and effort.

Some employers, such as the Australian Public Service, require applicants to undertake written, oral and cognitive assessments. Although, some departments do ask if you have a disability and whether you need additional facilities to participate in the assessment process, I am doubtful whether they are familiar with the particular needs of people who use AAC. I put down I need permission to use my communication device in the assessment. I don't know whether that was the right thing to say.

I perceive my journey to becoming a lawyer as the last frontier for with complex communication needs. If people with complex communication needs can have respectable professional careers, that will go a long way for us gaining full citizenship in society. This is why I chose to study law.

Going to College as a Strategy for Employment

**Beth Anne Luciani
Robert O'Gurek**

**William Adams
Sarah Lever**

“Success”

Sarah Lever

Success means setting and completing a goal. We can have many successes. A part of my successes comes from my faith in Jesus. I know I wouldn't be standing here speaking to you without the love and support of the people in the church and my family. A couple of Sundays ago my pastor talked on faith. She was telling the story of when Jesus and his followers were in a boat at sea. A great storm came rocking the boat. The followers were extremely afraid. They woke Jesus from a sound sleep. He raised his hands and stilled the body of water. He had to have much faith in his father and himself to do that. I was sitting there thinking my faith brought my successes. That is the most important partnership I have going. Jesus is taking my hand, and I am following his plans. Every success, big or small is joyous.

My name is Sarah Lever, and I am excited to be here at this wonderful conference. I have been remembering my educational experiences. They were emotionally hard on me and hard on everyone around me. Even now, I ask myself, how I graduated from public school especially when sometimes the environment wasn't the best. But I must remember the few teachers who were angels to me. Now, I am about to finish a community college with a degree in Internet technologies.

Everyone here has stories of success. One thing in becoming a successful person is advocating for your civil rights. When I looked up the word "advocacy" in Webster's dictionary, the definition said, "to support or urge, argument, or recommend publicly." I feel "advocacy" can be as simple as giving support to a person or trying to help that person get the rights he or she is entitled to by the United States laws and being a part of the human race. When a person is physically impaired, it is extremely important to have strong advocates, especially when the person is non-verbal and doesn't have an effective means of communication. Communication is indispensable. One example is when you have attendants helping you, and you want to tell them what you need.

When I was young, my mother and I were living in Chapel Hill. During my preschool years, we had no problems getting services -- nothing like what was ahead for us. The law saying that children with disabilities could attend public school was passed in 1975. That was a great landmark for people with disabilities. When I enrolled, the school's staff didn't have a clue what they were going to do with me.

Chapel Hill is where everyone thinks the schools are the greatest. Oh no, the experience

turned out to be a nightmare for my mother and me. First, I was put at a school with many stairs, even though that system had grade schools without stairs. I began school using a walker; the school staff said I was too slow. They told my mother and physical therapist to get me a power chair. When it got there, we had another problem on our hands -- getting the bus to pick me up from home.

My mother had no van at that time. We were told our home was on an unsafe road, because they had to turn into the driveway where there was a stoplight. So my mother asked the school to keep the power chair at school. The principle said "NO," because they would have to charge it every night, and they had no one to plug it into the wall and pull it out in the mornings. Also, they would have no way of measuring the amount of electricity my chair was using so I could pay them. The school system replaced him after he did a couple more things like that and the American Civil Liberties Union became involved. We had some friends who were lawyers -- that was a Godsend, because a new roadblock was placed in front of us every week.

In the eighth grade, my mother and I couldn't take anymore of this craziness, so we moved to Charlotte where my grandparents lived. I can tell you that that was the best move we could have ever made, because I had a couple of good years in public school. The Charlotte City Schools had much better special education classrooms for people with orthopedic impairments. But, I still needed people to do some advocacy work at times. When applying to college, there are certain rights that an individual with a disability must know about in order to advocate for him or herself. Section 504 of the Rehabilitation Act of 1973 "provides protection from discrimination on the basis of race and sex." This section also pertains to persons with disabilities by stating that, "No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program receiving federal financial assistance." Another source from the Internet stated that, "Both the Rehabilitation Act and the ADA clearly indicate that institutions of higher education must not discriminate in the admissions process, including the recruitment, application, testing, interviewing, and decision-making processes." The source continues by stating that the use of standardized tests is not prohibited, but it must be able to measure ability and aptitude rather than reflect any disabilities. Also, making preadmission inquiries about whether an applicant has a disability is not permitted, unless it is to remediate past discrimination.

There are times, however, when it's important to know your rights. In order to advocate for one's self, one has to know their rights. Become familiar with the Americans with Disabilities Act (ADA), and the laws in your state or country. The ADA prohibits discrimination and provides accommodations for individuals with disabilities. In my grandmother's magazine, *Modern Maturity*, I read an article titled, "The cost of modification." This article stated that the ADA requires businesses with 15 or more employees to provide reasonable accommodation to employees or prospective employees with disabilities. Furthermore, the author, Barrett Shaw writes that, "Companies are always ready to spend money on anything they think will give them a business edge: new technology, training for their employees, *etc.* Yet what many firms don't realize is that

modifying their facilities to serve people with disabilities is also good business; it opens the doors to a whole new contingent of dedicated and well-trained employee and enables a whole new contingent of paying customers to patronize their establishment." Another source of information about people with disabilities can be found on the Worldwide Web. I frequently use America Online for research purposes. When I was surfing the Internet I found a lot of information concerning the American Disabilities Act. "Ready, Willing & Available, A Business Guide For Hiring People With Disabilities," stated that on becoming employed, "Under the ADA'S regulations, the person with a disability generally has the obligation to request an accommodation, if needed." Furthermore, "The individual applicant may be the best expert on how to overcome the limitations of his or her disability when accommodating for a job." This is because that person knows himself or herself best.

My best advocate at this time is Gena Chambers from "CAP" (Medicaid) in Charlotte. She has gotten equipment and services I needed to keep me living at home, so I can have a life based on my own dreams of the future for myself. Without Gena and "CAP," I don't know what would become of me in this time of unknowing with the state money. We need to be self-advocates for our services, and have a strong network of support.

There are some groups who advocate for the rights of people with handicaps. We have a group in Charlotte called PAL's. Some of these groups have lawyers to fight for a person's rights. But, I have a couple of personal things I also go by.

1. Pick my battles, because sometimes it gets too much for you.
2. Know when to give up and cut your losses.
3. Things don't always work out the way you want them to.
4. DON'T GIVE UP ON LIFE!!!

Some professionals said I wouldn't be able to use an augmentative communication device and finish high school. Well, I am using my fifth AAC device, and I finished high school from the same school as my sister and brothers. I will be completing my college degree in sixteen months. My words for success are DON'T GIVE UP!

What are my strategies for the future? I am going to be employed in sixteen months by a new company that designs web sites. I am going to follow Jesus' plan for me. Also, I will do the best I can with what comes my way in life!

Before I end this presentation, I would like to give you a couple words of my limited wisdom. If you work or interact with a handicapped person, remember we are human beings. Please act as if we have brains and are not vegetables. Remember, there are devices to communicate our worries or wants. Now, for the augmentative communication users, we have the devices to turn in a person who did something wrong. I have had to do that to people who weren't doing their jobs. Look, I am still around; they didn't do anything to me. They might have wanted to do something. So, SPEAK UP for your rights.

ACETS required a Timesheet to be filled out by myself every two weeks. The Timesheet was divided into three sections, Goals to increase my skills, Goals to increase experience, and Goals to increased Social Network.

Goals to increase my skills as follows, to report to my Job Coach, Kevin, and Office of Vocational Rehabilitation Counselor Bimonthly, Improve telephone skills, and Pre-programming work related phases. Kevin has taught me how to compose a Professional Letter and a Professional Memo by the Electronic Job Coaching On-Line.

Goals to increase Experience as follows as Complete Community Based Work Assessment. I did one work assessment at Holy Redeemer Hospital last March. I completed a various tasks like entering Data in to a Microsoft Access Database and I did some filing.

Goals to increase my Social Network as follows as I have identified an Employer that will possibly hire me within a few months. I am in contact with the Employer every so often.

Within three days I would receive constructive feedback from ACETS staff. If my timesheet was not complete or late then Kevin was on me. ACETS required a strong commitment from me in finding a Job. Kevin and Diane do such great work for the four participants in the ACETS Program and I would like to say Thank you for their support. Also, I would like to acknowledge my parents and my attendants and Thank you.

I am asking the RERC to please continue to provide funding for ACETS Program. People who use AAC can find a job they want if they are willing to work at it. If anyone has questions then please feel free to ask me about the ACETS Program. Thank you for your time and your support.

My 15 Minutes of Fame: Winning an Academy Award for “King Gimp”

Dan Keplinger

Full-Time Professional Employment:

Working for the U.S. Naval Center

CONTACT _Con-466ACC3F2C \c \s \l Solomon Rakhman, B.S.

Road to Success: Working for a Major Insurance Company

James Protho, M.S.

SEQ CHAPTER \h \r 1Road to Success

Hello, my name is Jamie Protho. I am a computer programmer for Highmark Blue Cross Blue Shield here in Pittsburgh. I received my bachelor’s degree in from Edinboro University of Pennsylvania. I also received my master’s degree from the University of Pittsburgh.

Getting those degrees was not an easy task. In school, I had to work harder than other students. When I was in high school, almost every single evening, I would spend several hours doing homework. When other students had time to play, I was doing homework. The reason it took me so long to complete my homework assignments was because not only had I have to figure out the answers, I had to communicate the answers to a writer. The communication of the answers mostly took longer than the figuring of the answers. In college, the schedule made it easier to complete assignments on time because classes were not on back-to-back days. Test taking was a problem. A fifty-minute test would sometimes take me three hours to complete. Luckily I had professors who were understanding. I majored in computer science, which required a lot of math classes. This made tests and homework even harder to complete because it required a lot of symbols that many of the writers did not know look like. I had to either point to another symbol on the test or book or describe what the symbol looked like. Using a computer to do homework assignments was an option with the proper software package; computers were not an option for tests. Briefly, completing homework assignments and taking tests were not that easy.

After graduating from college, finding employment has been a long process and to be quite a feat. I spent many days looking in the papers for jobs that I was qualified to do and attending job fairs. The only thing I could get was a volunteer position as a data entry clerk for the Center for Independent Living. This was part of a program where I was to learn how to use my augmentative communication device in a real environment. Some time afterwards, I received an offer to be a research associate while going for my master's degree in rehabilitation science. Bruce Baker, who is an adjunct professor for the School of Health and Rehabilitation Sciences at the University of Pittsburgh, thought this would be a great opportunity for me. Bruce made it possible to get into Pitt to get my master's degree. Even though rehabilitation science was not my first choice of degrees and was not too eager to go back to school, I took the offer. It was better than sitting home watching television and collecting social security. Near the end of my grad school career, the Secretary of Labor came to give a speech about hiring people with disabilities. There were prospective employers in attendance. Of them was Joyce Bender, president of Bender Consulting Services, which is a company that finds jobs for people with disabilities. Joyce approached me with an offer to work for her company. Unfortunately the only positions she had were in Delaware. I did not want to relocate so I had to turn down her offer. Fortunately, a gentleman approached me with another job offer to work for the State as a web designer. Web designing was not what I wanted to do but I took the job hoping to transition into a programming job. I heard it is easier to get a job if you already have a job. I just wanted to get my foot in the door. During my time I worked for the State, I would see an old college friend who worked for Joyce Bender from time to time. He would tell me how great it was working for Joyce and tried to convince me to join Joyce's company. Because she knew I was employed, Joyce felt she did not need offer me jobs. But, when she heard I was not happy with the job I had, she started looking for a job for me. At the State job there was no room for advancement – to improve my skills. When a job opened up at Highmark, one of the companies she places

people, she offered me a job working on assignment there. A year later Highmark hired me. I am a computer programmer/analyst for them. Finding employment has been quite a long process.

Living on my own, I am able to manage attendant care. The following is a typical day for me. I wake up at around four-thirty. My attendant comes at around five-thirty. The reason I get up an hour before my attendant is that I need time to get ready for my attendant. When my attendant comes, the first thing she does is feed me. I cannot eat as soon as I get up. During that hour I am up, I watch television, call my mom, and maybe get on my computer. I have two attendants who get me ready for work. One of them works five mornings – one being on Saturdays; the other one works Fridays and Sundays. The one who works five mornings is able to get me ready a little faster than the other one. The faster one can get me ready in about a half-hour; the other one takes about forty-five minutes to get me ready. My morning attendants' duties include fixing breakfast, feeding me, bathing me, and dressing me. Mondays through Thursdays I am able to catch an earlier bus. On these days, I catch the bus around six getting to work before seven. On Fridays I catch the bus around 6:30 and get to work around 7:30. At Highmark, they have a flex schedule where workers are allowed to work any time they want as long as they get their required hours in. Some workers can even work extra time on nine days and take the tenth day off. This works out good for me because of my attendants. At work, I have an attendant who gives me my lunch around noon. This attendant works through an agency unlike my morning attendants. If my regular attendant cannot come, the agency finds someone to fill in for her. When I get home I have another attendant who comes to get me out of my work clothes and into more comfortable clothes, fixes dinner, and feeds me. Because my bed is down low, I do not need assistance getting in or out of my bed. Sometimes it is a couple hours after my evening attendant leaves when I get in the bed; other times it is a few minutes. This routine happens every workday. On the weekends, I have an attendant come once a day. I mainly let my attendants come at their convenience because my schedule is flexible. I have only two meals on weekend days. One meal is feed to me. The other meal I feed myself. It is usually a couple sandwiches cut in fours or deviled eggs because I can manage these without assistance. Unlike with my lunchtime attendant, when my home attendants cannot come to work, I take on the responsibility of finding replacements. I am pretty fortunate to have the attendants I have. They are very good about filling in for each other even on short notice. Managing attendant care can be a job in itself.

The means of transportation I choose is different than the average person with a disability living in Pittsburgh. Most of people choose to use ACCESS as their means of transportation. ACCESS is a special service for people with disabilities and the elderly. I prefer to use the regular bus for a number of reasons. First, I like traveling with “normal” people. I feel more “normal” if I am around “normal” people. I forget I have a disability. On ACCESS, I am reminded of my disability because I see other people with disabilities. Another reason I choose a regular bus over ACCESS is that ACCESS requires advance notice of trips. Sometimes I like to be spontaneous. I do not like to be tied down to the

times I arranged the day before. Third, ACCESS requires tickets as payment and each trip requires payment. On the regular bus, money can be used as payment. Passes can be used to ride as much as you want. These passes can be used for the week, month, half-year, or even the whole year. Using ACCESS, tickets must be purchased beforehand which is an inconvenience to me. The only advantage of taking ACCESS is they do go from door to door and go more places. Briefly, taking the bus is much more advantageous for me.

Being a computer programmer for Highmark is the job I have always wanted. In October it will be two years I have worked there. In that time I have worked on a few different areas. I was on the HIPAA project, which stands for Health Insurance Portability and Accountability Act. This act requires that the companies that have Highmark as their health plan be the same format. When I first started, I worked on the benefit enrollment and maintenance. Recently, I worked on referrals and authorizations. A while ago, my team was informed that our project was coming to an end. So we all had to find other positions. Fortunately, I found another position. I now work for the General Ledger Systems. Because programming jobs requires quality not quantity, I am able to meet deadlines. The time we are given to complete programs is more than enough time. I have not needed to ask for more time. The money I earn is more than enough to take care of the bills I have. I work seventy-five hours every two weeks making between \$30,000 and \$40,000 a year. The job at Highmark is the job I have always wanted.

In conclusion, this is how I got where I am today and how I manage. First, completing my school was quite a task. Second, finding employment was a long process. Third, managing my attendant can be a job in itself. Fourth, the means of transportation I choose is different than most people with disabilities. And, finally, I have been fortunate to obtain the job I have always wanted. Briefly, this is my road to success.

The Experiences of Undergraduate Students Who Were Taught by Lecturers Who Use AAC

David Trembath

School of Communication Sciences and Disorders, The University of Sydney

Typically, undergraduate speech pathology students are taught to work with people who use augmentative and alternative communication (AAC), yet have no input from those who use AAC. This represents a missed opportunity for students to receive expert teaching on issues pertinent to working with people with complex communication needs (CCN). At The University of Sydney, academic staff has attempted to address this problem through the formation of teaching partnerships with lecturers with relevant expert knowledge, skills, and personal experience, some of whom use AAC. Their expertise has meant that students receive functional information and instruction. At the same time these lecturers provide a catalyst for students to re-evaluate their beliefs, attitudes, and perceptions of people with CCN. In this presentation, I will discuss student perceptions of these partnerships and the benefits the partnerships provide for students. Ways in which such partnerships may be further enhanced will also be discussed

Teaching partnerships

During my third year of undergraduate study at The University of Sydney, I completed a unit of study related to working with people with Complex Communication Needs (CCN) associated with intellectual and/or physical disability. The content of the unit included "...consideration of underlying conditions and the particular communication and associated problems of children and adults with developmental disability, cerebral palsy, multiple disabilities, autism and autistic-like conditions, specific learning disabilities, attention deficit disorder, environmental deprivation, and alternative and augmentative approaches to intervention" (Balandin & Armstrong, 2001). During five 55 minute lectures, four expert lecturers, with CCN, three of whom were using AAC, and a parent of an adult with CCN, discussed issues that included public attitudes and perceptions of people with disabilities, the need for collaborative partnerships between professionals and service users, functional approaches to AAC, education and employment, advocacy and rights, and the importance of pragmatics and respect in facilitating communication between natural speakers and people with CCN. All lecturers are internationally recognised for their work in educating the public in relation to these issues.

Benefits for students

The lecturers provided students with expert knowledge, skills, and experiences and were able to relate these effectively. The use of personal anecdotes by all lecturers provided a powerful medium through which to illustrate key points, themes, and issues in a manner that we, as students, could easily conceptualise and understand. In this way the lecturers offered us the means to extend our understanding and awareness of pertinent issues to working with people who have CCN. The lecturers also gave us the opportunity to consider a range of practical and functional approaches for working with people who use or require AAC.

The lecturers were committed and experienced providers of public education. They were

able to anticipate and cater for a diverse range of perceptions and attitudes among students, along with many of the questions we were contemplating but reluctant to ask, and addressed these directly during their presentations. For example, several lecturers discussed pragmatic issues related to communicating with a person using AAC and suggested practical strategies for making it more successful (e.g., taking turns, speaking directly to the person using AAC rather than via their colleague, friend, or family member). For students who were not familiar with communicating with people using AAC, these insights and strategies helped reduce the anxiety experienced by many.

The lectures challenged students to reflect upon their own beliefs, attitudes, and perceptions towards people with CCN. This theme was consistently raised by lecturers and frequently formed the basis of discussions between fellow students following the lectures. The outcomes of this for students were difficult to ascertain. However, it is likely that the role of the lectures in triggering the reflective process, enhanced the students' development of more accurate perceptions and constructive.

Perceived purpose of the lectures

Throughout the undergraduate course, expert lecturers from outside the University were regularly employed on a casual basis to lecture on specific subjects. They were selected on the basis of their knowledge, skills, and experience in the particular subject, along with their ability to present the information in a way that would support student learning. It was apparent that these same criteria were naturally applied to the five people who lectured during our disability studies unit. I believe that the adherence to these selective criteria was fundamental in ensuring not only that we received quality teaching, but that the students perceived the lecturers as experts on the information and issues they presented.

Nevertheless, students expressed differing perceptions in relation to the purpose of the lectures and the credentials of the lecturers. A common perception was that the lecturers were there because they used AAC, rather than because they had expert knowledge and experience to share. A striking disparity between student evaluations of these lectures and others presented throughout the course was the almost unanimous endorsement of the lecturers who used AAC and their presentation style in the absence of criticism regarding the content of the presentation. The outward indicators of student perceptions suggested that the majority of students focused primarily on the person presenting and the fact that they were using AAC rather than on the content of their presentations (Balandin & Armstrong, 2001)

It is possible that student perceptions of the purpose of these lectures related to their own preparation and familiarity with the issues that were to be discussed. Guest lecturers primarily discussed issues and concepts that had been raised in previous lectures. However, for a number of reasons (e.g. absence, poor concentration in previous lectures, failure to take or review notes, time between lectures) students may not have been able to draw links between information and issues previously discussed and those presented by the guest lecturer. This failure to map new information onto established concepts may

have led some students to perceive the lectures as a collection of anecdotes and personal opinions rather than an in depth and extended exploration of previously discussed theoretical issues based on personal experience and professional insights.

Future directions for teaching partnerships

From a personal perspective, the guest lectures were instrumental in developing and affirming my interest in the field of AAC. Of particular attraction was the emphasis placed by lecturers on the need to formulate functional goals and approaches through the development of collaborative partnerships based on mutual respect. Through their teaching, the lecturers challenged me to reflect upon my own beliefs, values, perceptions, and attitudes towards people with CCN. I agree with the majority of students who reported that these lectures were valuable for their learning (Balandin & Armstrong, 2001). I support the ongoing development of the teaching partnerships.

In considering ways to enhance the outcomes for students, Balandin and Hines (2003) suggested that small group teaching, involving people with expert knowledge, including those who use AAC, would be advantageous for students. I support this suggestion. The small group context lends itself to the exploration of individual participant's ideas through the exchange of questions, ideas, and information. This is in contrast to the didactic delivery of information common in large class (90+) lecture format. The capacity for lecturers to probe the understanding and awareness of individuals in relation to pertinent issues is facilitated in the small group context. Thus, small group format would help ensure the focus of learning is on the issues presented by the person using AAC rather than the person.

Balandin and Armstrong (2001) suggest that self-reflection using personal learning journals may result in students gaining a greater understanding and appreciation of the issues presented in the lectures

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<EndNote><Cite><Author>Ramsden</Author><Year>1992</Year><RecNum>955</RecNum><MDL><REFERENCE_TYPE>1</REFERENCE_TYPE><AUTHORS><AUTHOR>Ramsden, P.</AUTHOR></AUTHORS><YEAR>1992</YEAR><TITLE>Learning to teach in higher education</TITLE><PLACE_PUBLISHED>London</PLACE_PUBLISHED><PUBLISHER>Routledge</PUBLISHER></MDL></Cite></EndNote>

(Ramsden, 1992). I believe this approach has significant merit, however I would caution against making this an assessable task as it may compromise the honesty and depth to which a student feels comfortable exploring their own attitudes, beliefs, and perceptions towards, and in relation to, people with CCN. Small group reflection is an alternative to the use of written journals and has the additional benefits of allowing groups of students to present diverse opinions and perspectives with the inbuilt facility for peers to constructively debate these. This was made evident to me through participating in a focus group for research conducted by Balandin and Hines (2003).

Conclusion

Teaching partnerships involving experts in the field of CCN and AAC constitute an effective means by which to better educate undergraduate speech pathology students. Input from experts in AAC during the undergraduate training period may result in the development of more accurate and constructive beliefs, attitudes, and perceptions by students. Through a developed understanding and awareness of pertinent issues, students are in a better position to form positive and effective collaborative relationships with service users based on mutual respect in clinical practice. The evolution of teaching partnerships to include small group teaching and greater reflective practice by students represents a possibility for the further enhancement of an already effective approach.

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The Importance of Starting AAC Early

Irene Hohn

HARD COPY ONLY

Getting a Job – The Nuts and Bolts, A Conversation

Kevin Williams, B.S.

Randy Kitch, B.S.

Working As A Professional In The Disability Field

Randy Kitch

My name is Randy Kitch and I'm the Consumer Advocate for North Bay Regional Center in Napa, CA. This is a non-profit regional center along with twenty-one others serving people with developmental disabilities in state of California. I'm also a Board member of the Supported Life Institute in Sacramento, CA, which educates people with disabilities and puts on conferences on many subjects.

This panel is about working as a professional in the Disability Field. Well, first I think

we need to define “professional” because to me, everyone here is one. Thus, I’m defining it as someone who gets paid serving people with disabilities. Of course, many people here have visible or unseen disabilities. Anyway, working in the Disability Field is the same as working in any other field of work, only I was born in this field. I still needed to obtain a college degree, make contacts in the community or NETWORK, and have support from my family and friends.

I started my professional career in 1975, at the age of 24 years, by helping to start a group home for five persons with disabilities. I helped to start a non-profit agency in Topeka, KS and the Board of Directors hired me to be the Program Director. I hired and fired the staff, implemented training in cooking, house keeping, socialization, recreation, money management and personal hygiene. The name of the organization was Help Unite Human Relations, HUHR. To this day, I believe that helping unite human relations would have beneficial rewards across educational, governmental and personal systems crossing cultures, borders and neighborhoods.

My job also involved attending lots of community meetings and being on committees. This is called playing the political game. Another job opportunity developed at Kansas University in Lawrence, KS this was a National Coordinator of a grant to train people with developmental disabilities self-advocacy skills and human and legal rights across the country. I had to update my resume, prepare for the interview, and even wore a tie. For me, ties can be tricky. I could accidentally strangle myself!

Kansas University hired two co-workers and me, sending us across the nation giving workshops training people to become their own self-advocates. When we visited California I fell in love with the countryside. I really loved that job! That grant was only for three years. I was then offered a position at the Independent Living Center in Berkeley, CA. So in 1980, I packed up my worldly goods and moved to the land of earthquakes, California. Yep, I thought I had a job and I was staying with a friend until I could get an apartment. When I arrived at the San Francisco Airport, my friend told me the funds for the job didn't come through. Needless to say, this did not make my cup runneth over with joy. I said to myself, "God is really testing me." I had to apply for SSI and SSDI and start looking for jobs. Then in December 1980 my SSI/SSDI was approved and I was eligible for an apartment and I moved with a live-in attendant. The job search continued and on April 1, 1981 I started a job as the Executive Director of an Independent Living Center in Santa Rosa, CA. We served all people with all types of disabilities. The services we provided were attendant care, benefits counseling, support groups, advocacy, and information and referral. The agency had a good health plan so I wasn't dependent on Medi-cal. I lasted as the Executive Director four years. I decided management wasn't my cup of tea and gave them my two-month notice. Yes, I said two month, not two weeks.

I thought people knew me in Santa Rosa and it would be easy getting a job. WRONG! I had to go back on SSI/SSDI. I moved to Stockton, CA to get advance training on editing videos. Well, the day before I was supposed to move, my friend called saying his boss decided I couldn't touch the equipment because I wasn't a staff member of the State of

California TV Center. The friend said not to worry about it because I could appeal once I was there. When I arrived at the TV Center I tried all types of appeals, which were not successful. Keep in mind; this was a state agency serving people with developmental disabilities, which I fell under because I have Cerebral Palsy. This was also before the American with Disabilities Act was law. Sure, I could have sued under 504 of the Rehabilitation Act. At that point, I chose not to put others and myself through the hassle of court, etc. What I wanted to do was work for competitive pay and support myself. So I took a slight detour and I volunteered temporarily a couple of blocks away at the Technical Resource and Activity Center of Stockton, which was a part of the Stockton Developmental Center. By one year, I was hired as a fulltime employee as I had demonstrated that I had great work skills, knowledgeable skills in interacting with others and could offer another perspective to the assessment center.

Our team did assessments in augmentative/alternative communication, environmental control, and vocational/computer access. I videotaped and edited the assessments with a modified video camera on an upright dolly. My job was also to schedule the assessments, get the assessment team together and help write reports. I was hired by the State as the Individual Services Coordinator. This was where I met my wife to be Brenda; only then we were in other relationships. We were co-workers at Stockton Developmental Center for two years. Needless to say, I never got the video training I needed but that did not stop me from learning by experimenting on my own with some video editing equipment and tips from others.

Then, I wanted to be an Assistive Technology Specialist and be the Assessment Coordinator at Sonoma Developmental Center, which was the largest institution in our nation and the world with 1,000 residents and 2,000 staff persons. Yes, I moved again to a small town called Glen Ellen. The job was the same as at Stockton but with more money. Anyway, I lasted at Sonoma Developmental Center four years because my supervisor and I had differing values and concepts of what constituted adaptive equipment. He chose to limit what his definition of what assistive technology could do for people. His focus was on mobility aids, which is important. There was also some resistance from some persons from the unit residences and the speech therapy department needing more training about the more sophisticated adaptive equipment. However, only moving the people from place to place did not cover the whole person in interacting fully in his or her life. I kept repeating to many ears that more people would benefit from the many ranges of environmental control, communication and enhance living gained from extensive assistive technology.

I was approached to take a new job by the executive director of the independent living center that I was the director of back in 1981. He called and offered me the position of branch manager to open a new branch office in Napa. At first I said no, because it was a cut in salary. We were looking into buying a house, which was my first. Then I thought about it and decided why not. It would be a challenge starting a new branch and maybe I should give management another try. Well, guess how long I lasted at this job? Three years! Found out I really don't like management so I resigned and went on State Disability for ten months before I was hired at my present job. Yes, I'm still there and I

really love it these past three years. I'm called upon to work with self-advocacy groups, attend meetings, and consult with staff and organizations in our three-county area and beyond. There's never a dull moment.

The reason I have told you this is because I have had several jobs and being a professional in the disability field, or any work field, is more than just making a good salary. Personally, I feel we must enjoy our jobs and be happy doing them. If we aren't then it is time to move on. Although, there are times you need to stay put and attempt to readjust your mindset on how you feel about your work. This would give you time to look into finding another job to graduate into. Being a professional also means taking responsibility, asking questions, being on time for work and meetings, supporting your co-workers and vice versa. Above all, being a professional means working together with others as a team. Thus, I have decided to change my definition of a professional to... "Someone with expert skills in a certain area or areas." Sure, a good salary helps... but you do not need to be a paid employee to be a knowledgeable and teaching person. If you are able to share even in a voluntary capacity it could turn into paid work there or somewhere else. You only need to be in the right place at the right time and BINGO!

Thank you.

Making It: A Ph.D., A Wife, and a Job
Robert Segalman, Ph.D.

Working in Marketing and Public Relations for AAC Companies
Anthony Robertson
David Morris, B.Ling, M.A., DipCCS, MRCSLT

Rick Hohn

Summary:

In this presentation, the presenter, an AAC consultant, will discuss his supervisory role in the Consumer Representative Program that included its development and in raising the bar of professionalism of consumers representing for DynaVox Systems.

Proposal:

The AAC users are an increasing value to device manufacturers in representing their companies - raising the bar of excellence. As consumers, they pass on their knowledge gained from experience to professionals, students and family members. This is in knowing that other users will reap the benefits. Teachers and therapists know that proficient device users utilize their equipment- everyday - for all day. These professionals want their opinions and feedback.

The presenter will discuss his AAC consultant's supervisory role for the Consumer Representative Program of DynaVox Systems, which is the world's leading provider in AAC. The program's development and in raising the bar of professionalism that is the highest of any AAC

manufacture will be discussed. He will also share the psychological benefits of being employed to fulfill his dream.

Levels of Participation

The Consumer Representative Program that the presenter helped to initiate has three levels of participation. They range from presenting at conferences with minimum assistance from the Education Department to helping in the booth. More specifically, the three levels are as follows:

The first is the Red Level

With the presenter participating at this level, the Consumer Representative's responsibilities include independently drafting all proposals for state and national conferences with proposals being research-based with accompanying references. He receives edits from members of the Educational Department, completes the proposal, and submits papers to the conferences. Upon acceptance, he conducts presentations at state and national conferences and independently develops all handouts for presentation. After each conference, he writes a newsletter column that provides a summary of recent presentation. Besides tending to his personal work, the Consumer Representative mentors colleagues with conference submissions as assigned, and meets all deadlines.

The Education Department assigns an education specialist who supports the Consumer Representative throughout the process, and provides assistance with editing, printing and resources

The second is the White Level

The three current Consumer Representatives at the White Level assist and/or co-present at local, national, and regional conferences as assigned. They also assist the Education staff with presentation proposals, content and handout development.

The Education Department assigns an education specialist to work with the Consumer Representatives and provides guidelines of the presentation process, as needed.

The third is the Blue Level

The Consumer Representatives at the Blue Level provide local support to DynaVox Sales Associates and create pages on their DynaVox to discuss current product and answer frequently asked questions.

The Sales Representative identifies and contacts local Consumer Representative. He or she oversees interaction with consumers and provides feedback.

Furthermore, all Consumer Representatives are fully supported financially at conferences.

Challenges to Meet

There are many challenges in the Consumer Representative Program that the presenter has to take into consideration. They are as follows:

Because the Consumer Representatives are scattered around the United States of America, one of the biggest challenges has been to keep in contact with each other. This is to learn to improve their interaction with customers about top of new product updates and releases. Newsletter and email correspondences are the two main ways that this communication has been achieved. Also, the Education Department and the presenter drafted up some Consumer Representative Guidelines.

Consumer Representative Guidelines

Professionalism is highly stressed for the Consumer Representatives whether it is conducting business with customers or interacting with each other or employees at DynaVox Systems with the following expectations:

As Consumer Representatives, they represent Sunrise Medical and DynaVox Systems. The company doesn't take or support political positions and it is inappropriate for associates to express or convey such position in any while on company premises or while conducting company business as providers, or patient locations. T-shirts, slogans, and cover stickers that advertise personal opinions are prohibited.

Appropriate professional attire includes slacks, khakis, blouse, pant suit or business dress for women and dress or golf style shirt for men. DynaVox shirts, provided by the trade show coordinator, are required for conferences.

Meals eaten at the hotel are charged to the company credit card and meals, accompanied by receipts eaten outside of the hotel, are reimbursed for the Consumer Representative and the Personal Care Assistant (PCA). The company pays for group meals with DynaVox's Associates transportation to and from the restaurant only for dinner. The consumer Representative or the PCA pays any activities after the meal.

DynaVox Systems pays for one hotel room per Consumer Representative and his or her (PCA). If a representative doesn't wish to share a room, he or she must make extra payment arrangements. The Travel Coordinator sends credit authorization to the hotel to cover room for the duration of the company warranted stay, tax and meals.

The Travel Coordinator makes all airline reservations and arranges transportation arrangements to and from the airport for consumer Representatives and their PCA's.

DynaVox Systems also has requirements of PCAs with the Consumer Representatives in charge. It is expected that they are able to independently manage and meet the needs of the Consumer Representatives throughout the trip and are responsible for collecting receipts and assisting the consumer Representatives with expense expenditures. Other requirements include communicating effectively and professionally with the Consumer Representatives and DynaVox Associates.

The Development of the Consumer Representative Program

The presenter will discuss how the Consumer Representative Program was born out of his desire to see other high-end DynaVox users represent the company – breaking down the false perception that he was the only person to use his device proficiently. DynaVox Systems recognized his leadership and asked him to give trainings to other prospective representatives in sharing his knowledge as a consumer over the years. Such knowledge included training how to work in a booth, write proposals for conferences and deliver presentations. The company saw the value in the program, and higher the expectations are placed of the Consumer Representatives to make them deal professionally in a sophisticated field of AAC.

This has resulted in the good feeling that the presenter gets out of his leadership as well as the normal work-related stretching of character in making unpopular decisions among his colleagues. Overall, working for DynaVox Systems for seven years has given him a sense of high self-esteem and pride of being employed that in spite of his disability has been unimaginable.

Biography of Rick Hohn

Rick Hohn is a pastor in Vista, CA and an AAC consultant for DynaVox Systems supervising its

new Consumer Representative Program and speaking at national conferences. Rick also was a Peer Reviewer for a presentation on the USSAAC Website and published his autobiography entitled, "More Than a Watchmaker."

Obtaining Funding for a Major Project

Jon Feucht
Jennifer Lowe, B.A.
Anthony Robertson

Jennifer Lowe, Executive Director, SHOUT

Westinghouse Electric Corporation along with the Pennsylvania Office of Vocational Rehabilitation established SHOUT in 1990. SHOUT is an acronym that means, Support Helps Others Use Technology. SHOUT, a non-profit c3 organization, was established to advocate for a specific group with disabilities. This group of people was those who were non-speaking and were unable to use speech and hand signs. More than a million people in the United States were disabled. 150 of them were gainfully employed. Fewer than 100 were disabled people who were unable to speak or use hand signs.

In November 2001, SHOUT, made an important decision. That decision was to name a person to be the Executive Director. This individual would be solely in charge of their fund raising for their conference for augmented communicators, The Pittsburgh Employment Conference. It named Marion Smith, an augmented communicator, to fill this position.

Jennifer was born with Cerebral Palsy and relied on a communication device to speak. My initial augmentative communication device was provided to her through a grant her speech pathologist wrote, when she attended Pioneer School. Initially, Marion rejected the Light Talker, because it had the echo voice chip, which was unintelligible. Once that the voice chip improved, I excelled in my use. The communication device was called the Light Talker.

The Light Talker enabled me to be partially mainstreamed and, eventually be accepted into Edinboro University. I graduated with a Bachelor's degree in Liberal Arts by majoring in Specialized Studies. After I graduated, it was time for me to get another augmentative communication device. After careful investigation, I decided on the Delta Talker.

A few years after I graduated from Edinboro University, and a software company offered me a part-time position as the Lead Ambassador of The Pittsburgh Ambassador Program. The Ambassadors met once a month for three-hour meetings. We discuss one personal issue, one business or educational issue, and communication aid problems. In time, other augmented communicators were invited to the meetings, where we grew to between five and nine participants each month. This is an enriching time for us, because we all

try to use our communication aids during the whole meeting.

Other individuals had been observing how well I communicated and presented myself. The Board of Directors of SHOUT felt that I was qualified for their Executive Director position, which was another part-time position. I accepted this position. Now I have two part time positions that often make for a full week's work.

In order to enable me to be effective, I requested that SHOUT hire someone to train her and provide the necessary tools. They hired Laurie Nicholl from Nicholl-Brandt. Laurie came to my house, saw my computer set up, and determined what would make me look and be professional. Through Laurie, I gained template letterheads with the SHOUT logo, instruction how to do business letters, and a sense of what was expected from me. This didn't take one visit from her. It took several. At this time, my training hasn't ceased, although it has gotten to be less frequent. Communication between Laurie and I became to be mostly on the phone and through E-mail.

My mode of transportation, access, was unreliable; she agreed to a driver drive her van, when she needed to be at a meeting at a specific time. This eliminated a lot of anxiety for me. ACCESS Transportation would undoubtedly get me to a fundraising meeting late, more often than not. ACCESS Transportation has a policy that allows its vans to come ten minutes early or twenty minutes late, and still be considered to be on time. That would make me appear to be irresponsible. That wouldn't be good. With a personal driver, it also provided me support person more time to prepare for my meetings. This has worked well.

Next, I requested that SHOUT had to consider another component for my being the Executive Director. That component was paying my support person. SHOUT recognized that this individual was important for me to be effective. It was extremely important for them to compensate my support person's hours. Therefore, they incorporated her pay in the fundraising requests. Most of the fundraising received did go to this year's Pittsburgh Employment Conference but, in the beginning, some of it did go toward my support person's compensation. The Office of Vocational Rehabilitation (OVR) was a major financial support for this. OVR stipulated that I had to come into the office, at least, once a week for SHOUT to receive their financial support. Therefore, Jennifer started coming into the SHOUT office, on Mondays. The Pennsylvania Office of Vocational Rehabilitation was also instrumental in SHOUT obtaining funds for this.

To my delight, SHOUT obtained funding for the Pittsburgh Employment Conference. The Verizon Foundation and the FISA Foundation awarded funding to SHOUT. SHOUT next partnered with the University of Pittsburgh's School of Health and Rehabilitation Sciences for funding and they are funding in a variety of ways. In the future, we will be inviting foundations for site visits to our office.

Once, I had to attend an engagement on a Saturday. This was to build relationships with a Masons group in Pittsburgh which SHOUT hoped would lead to a significant funding donation. During this event, Jennifer mingled with the Masons and their families,

spreading the mission of SHOUT. The Masons did give contributions to SHOUT for the Pittsburgh Employment Conference. Therefore, my networking with SHOUT was a success.

Another group that I talked to was the East Rotary Group. There I told them about SHOUT's mission, the Pittsburgh Employment Conference and the Urban Camp for young augmented communicators. The chairperson was enthusiastic about SHOUT's mission that she collected money right then and there from this group.

One of SHOUT's Board members challenged me to attend three fund-raising meetings a month. Her gaining more funding for the Pittsburgh Employment Conference was the purpose of this suggestion. Jennifer accepted this challenge.

Being the Executive Director of a 501-c3 organization was a true learning experience for me. Already during my term, I learned a nice proportion of the role of an Executive Director. One significant lesson that I learned was that not every foundation granted money to organizations like SHOUT, especially when the economy had a change like it did recently. With that came the lesson of persistence and inquiring the reasons why a foundation turned down SHOUT's proposal. Laurie Nicholl suggested that she along with SHOUT's Secretary/Treasurer make these inquiries and give the information to me. Another significant lesson I learned was that when funding didn't come in, the Executive Director or her support person didn't get paid. Fortunately, SHOUT's Board came to the decision to allocate a proportion of the funding coming in, to an account specifically for her and her support person's pay, which will be implemented in the future. Finally, I learned that another duty of an Executive Director was, having a lot of knowledge of the financial budget of the organization. My expanding knowledge in this position will never cease which, will keep it exciting for me.

Allow me to look toward the future of SHOUT's Executive Director. I see myself going into the office more than once a week, even when we have a Board meeting that week. My job will be much busier once I become known as Executive Director of SHOUT by foundations and non-profit organizations. I am working hard to do that using the Pennsylvania Foundations Directory, by sending letters, site visits, and phone calls. Of course, an increased number of hours for me and my support person is required. Since this paper was written, I have received a computer from the Verizon grant. I can now accomplish more of her duties more effectively than I do from home from the SHOUT office. This increases my fundraising abilities for the Pittsburgh Employment Conference and SHOUT's mission: the study of and advocacy for employment of people who use augmentative communication. The decision to appoint me to be the Executive Director was a bold move. SHOUT looked passed my challenges to see my working potential. The Board lived up to their original idea of helping non-speaking people who are unable to use speech and/or hand signs. With my continued efforts, the Pittsburgh Employment Conference's funding will hopefully increase which will provide more opportunity to affect more augmented communicators.

AAC and Cell Phone Usage: An Off-the-Shelf Solution ^{1,2}

**Paul Pecunas
Diane N. Bryen, Ph.D**

Institute on Disabilities/UCE
Temple University

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The purpose of this article is to describe the importance of cell phones in the lives of people who use wheelchairs and AAC technologies, to illustrate some simple “off-the-shelf” solutions, and to demonstrate to cell phone merchants that there are underserved customers who can benefit from their service.

The Need for Cell Phones for People who Rely on AAC

For the past five years, we have come to recognize the importance of cell phones for individuals who rely on wheelchairs for mobility and augmentative communication devices for face to face and tele-communication. Whether the forum has been a conference (e.g., the Pittsburgh Employment Conference), a stakeholder forum (Technology Transfer Forum, 2001; the State of the Science Conference on Augmentative Communication, 2001), or postings to an international Listserv for people who use AAC (ACOLUG), the need for cell phones has been consistently voiced. Expressed reasons for cell phone include:

- Health and Safety (e.g., a means for contacting someone if stranded or if your wheelchair breaks down, risk reduction for crimes or abuse. emergency or routine communication regarding health concerns);
- Managing transportation issues (e.g., contacting Para transit about a needed change in time or location);
- Communicating with employers (e.g., job related topics, communication while traveling);
- Communication with family members, friends, or attendants; and
- Image enhancement – demonstrated communication competence and versatility to the public.

“Off-the-shelf” Cell Phone Solutions: One Case Study

People who use AAC technologies have requested that cell phones be built into augmentative communication devices. However, currently this solution has not been implemented by any of the major communication device manufacturers. What is currently built into several communication aids is the ability to dial phones through the device itself, rather than via the telephone-dialing pad.

One solution that does not rely on any specialized technology and can be purchased at a local cellular phone distributor (e.g., Cellular One) includes the following generic components that are used for mounting a hands-free cellular phone in a car. This includes:

Component 1: Cellular phone as shown in Figure 1.

Figure 1. Nokia 5100 (cover not included)

The cell phone kit is from Nokia Model 5100 series/CARK-91US. This kit and phone were recommended for the following reasons:

- It is durable,
- It has better overall quality,
- It is more user friendly;
- It has been around in one form or another for at least five years and has had all the bugs worked out of it;
- It offers all the features you would need including:
 - Caller ID
 - 99 name phone book storage
 - One touch dialing
 - Voicemail notification
 - Text, voice and phone-to-phone text messaging (if it is supported by the carrier)
- It also offers the best battery life which should not be an issue in This case as the phone will most likely be in the kit 99% of the time and therefore powered and charged at all times by a 12 volt wheelchair battery (note, it is important for the customer to take the phone out and drain it once or twice a month and then charge it on the wall charger (included in the kit) to avoid hurting the battery on the phone.

The website for Nokia cell phones is: www.nokiausa.com

Component 2: Cradle and Mount - positioned and secured to an accessible place on the wheelchair as shown in Figure 2

Figure 2. Pedestal mount

The mount for Paul's cell phone is called a pedestal mount manufactured by Panavise. This mount was select because it is the most durable, user friendly and sturdy item in its class. Refer to their web site at www.panavise.com/nf/comm/cell_slimline.html for more information about this mounting system.

Component 3: Battery pack attaches the cell phone to your wheelchair battery as shown in Figure 3 so that the cell phone is charged through the power source produced by the wheelchair's 12-volt battery. Like cell phones mounted in a car or charged through a car's cigarette lighter, no other source of electrical current is needed for charging the cell phone.

Figure 3. Battery Pack

Component 4: A standard speaker is attached is attached to the wheelchair arm as shown in Figure 4 so that cell phone user can hear the person on the call. This component is needed if you are not able to hold the phone to your ear.

Figure 4. Standard Speaker

Component 5: A standard microphone is also used so that the phone can receive the synthesized or digitized speech being generated by the communication device or the natural speech of the person who uses augmentative communication. This microphone is the same as that used in a car to increase "hands free" use by a driver. The positioning of the microphone on a wheelchair is critical so that it can receive sounds from both the person's voice and the person's communication device. Positioning of the microphone for Paul is illustrated in Figure 5.

Figure 5. Standard car microphone

The costs of all of 5 components and the mounting of them on Paul's wheelchair were \$249.00. This was purchased through Cellular One in Meadville, Pennsylvania, so price may vary depending on location. This cost does not include monthly service cost which is approximately \$35.00 per month for 300 minutes usage anytime and to anywhere in the United States when calls are placed from Meadville, Pennsylvania.

Finding a Cell Phone Solution

After the fact, this solution seems quite simple, since all of the components are “off-the-shelf”. Also, mounting the phone on a wheelchair is not qualitatively different from setting up a hands-free cell phone in an automobile. However, the journey in finding the solution was not so direct and simple. According to Paul:

“I visited local a cell phone store in Meadville, Pennsylvania, asked the salesman about a cell phone for myself, and received the following answer, ‘you can’t put a cell phone on a wheelchair.’ Subsequent to that visit, I went to another cell phone store, examined solutions for the car, and went to the store where a friend had purchased her cell phone -- Cellular One. Again I asked about the use of a cell phone given that I use a communication device and a wheelchair. That technician said that he could do it and we made an appointment to have it installed in two weeks.”

Here’s what the technician, Dan, who installed Paul’s cell phone had to say:

“Now for your specific installation. I basically had to engineer this on the fly. I worked closely with Paul and his assistant to find the best location for each element of the kit.

The first thing one needs to have is a 12-volt source. You can't continue until you have found that or gotten it adjusted to 12 volts. The best thing would be to contact the wheelchair's manufacturer or the power suppliers' manufacturer. Paul's was easy as it had two 12-volt sources.

The next step that needs to be addressed and was the last we did address is moisture. The phone and kits have to stay dry. They can't get wet or they will be ruined and void the warranty. Paul's assistant addressed most of the elements for that issue. I am still not satisfied with how I have handled that. I imagine if you had more time (which unfortunately I didn't and don't have) you could manufacture some impressive things. We used a plastic bag for the junction box. Paul's assistant had her husband make up some covers for the cradle and speaker, that I did not see as they were not there at the time of installation. It is just important that they be kept dry and free of moisture.

I used a mirror mount antenna as it is designed for a round tube that most trucks use for mirror supports. As for the location of the speaker, cradle/pedestal, microphone, and junction box, it was a collaborative effort. I would hold the items in different locations until we found a

comfortable spot for Paul to use it. You want to keep the speaker and microphone away from each other to avoid feedback. We mounted the speaker on the opposite side of the wheelchair, so it was out of his way and away from the microphone. One challenge we did run into is that Paul's wheelchair gets torn down somewhat when being transported. We had to leave enough slack so that it could be taken down without cutting or ripping the kit.

So other than the two issues of moisture and tearing down the wheelchair, it is pretty much a custom job for each person's situation.

The kit was wired to the positive and negative sides of the wheelchair battery and has inline fuses so it will not hurt the battery pack other than blowing the fuse should there be a problem.

An individual [who uses an AAC device and wheelchair] who would like to do this will have to work closely with the technician who is going to install it as far as location and protective measures for the kit. So communication with your installer is key and make sure they are a reputable installer. You shouldn't have this system installed by a weekend warrior or "shop rat" as they call themselves (someone who hangs out at an installation shop, but is not employed as one). It should be a professional to do the work and preferably a Nokia certified installer.

Now there are other kits out there and phones. I have to say that this Nokia 5100 series is your best option out there. A lot of the other kits are more expensive and just not as good a quality."

Dan from Cellular One in Meadville, Pennsylvania

From Paul's experience, several points are worth noting. First, have the technician at the store install the phone. This is critical to ensure that the warranty will be valid. If you have someone else install the phone, even if it is just as an effective installation, it may invalidate the warranty.

Secondly, when you have your cell phone installed, take the time to try it out – both sending and receiving calls. This is important for several reasons. You want to ensure that all components are working and also that all components are positioned in a way that is best for your access and use as shown in Figure 6.

Figure 6. Positioning of the Cell Phone

How the Cell Phone Works

Now that you are familiar with the components needed for a functioning cell phone system and how they were installed, a brief description is provided on how the cell phone works and what features are most helpful. This particular cell phone is a regular hands-free cell phone purchased through a local Cellular One store. According to Paul, helpful features include:

Auto answering - This “hands free” feature is very handy since it allows the phone user to answer incoming calls automatically.

Auto hang up - like auto answering, this “hands free” feature allows the phone user to hang up automatically once the call is completed.

Voice message – If the phone is not on or the user is not available, a voice message can be left by the caller for later retrieval by the phone user.

Text messaging – This feature allows the caller to leave a text rather than a voice message.

Lights on/off – This feature lights the screen and the keypad making it easier to see especially in a darkened setting.

Telephone book –Frequently dialed telephone numbers can be stored by the user in order to reduce memory demands (what was that telephone number) and motor demands. Instead of remembering the telephone number for the Institute on Disabilities and then having to dial it (215 204 1356), once stored the user only has to access the telephone book and scroll down to the stored Institute on Disabilities telephone number. Another alternative is to remember the location where the number has been stored and then hit the 2-digit number that the phone user has preprogrammed (e.g., 05 for the Institute on Disabilities).

Making a Call. **Making a telephone call is quite simple. If the number is stored in the phone book, just use the “down arrow” to scroll down until you reach the desired number and then hit “call.” If the telephone number is not stored, you will need to dial the number and then hit “call.”**

Receiving a Call. Again, receiving a call is also quite simple. If the “auto answer” feature is on, you don’t have to do anything. The call will come through and you can receive it and begin your telephone conversation. If the “auto answer” feature is not on, just push any button on the phone pad and begin your telephone conversation.

Beyond this cell phone solution: Some suggested improvements

Given this particular cell phone solution (and we are sure that there are others), here are a few design modifications that would improve cell phone usage by individuals who use AAC.

Larger Buttons would improve ease of access from both the visual and motor perspective;
Water Proof Cover would increase the range of use so that outdoor use would be better especially when phone use is needed in the rain;
Voice Activation that would recognize both synthesized and natural speech;
and
Video Cell Phones so that the unfamiliar receiver would see that the person initiating the phone call uses an AAC device and therefore needs more time to communicate. This would reduce the frequency of “hang ups.”

Summary

Cell phone use by many people who rely on AAC is available today. Capitalizing on current “hands free” car phones, use of a little imagination and problem solving can result in a cell phone solution for many today. The solution presented in this paper is but one. If you have other cell phone solutions that you would like to share with other individuals who use AAC or that we might pass on to local cell phone distributors, please email Paul at [HYPERLINK mailto:Coonster@toolcity.com](mailto:Coonster@toolcity.com) Coonster@toolcity.com.

¹ This article was written with support, in part, from the RERC on Communication Enhancement, through a grant from the NIDRR.

² A special thanks for Dan at Cellular One in Meadville Pennsylvania for his “engineering on the fly” and for providing us with the specifications and installation description.

Institute on Disabilities/ UCE - Temple University - 10/09/01

Opening Up a "Whole New World": Employer and Co-Worker Perspectives on Working with Individuals who use Augmentative and Alternative Communication

**David McNaughton, Ph.D, David Chapple, B.S.,
Janice Light, Ph.D., Stephanie Gulla, M.S., CCC-SLP
The Pennsylvania State University**

Introduction

Previous studies have shown that employer and co-worker attitudes influence employment success of individuals who use AAC (Light et al., 1996; Odom & Upthegrove, 1997; McNaughton et al., 2001; McNaughton et al., 2002). Still, much of this evidence is based on the opinions of the individuals who use AAC. This study was designed to help fulfill the need for the perspectives of employers and co-workers who work with individuals who use AAC.

In this study, 14 employers and co-workers who work with individuals who use AAC completed a survey, answering questions in regard to:

- the benefits of employment
- the challenges to employment
- the supports needed for successful employment
- recommendations for improving employment outcomes

The benefits of employment for the individual who used AAC included:

1. Positive social interaction

I really believe that [Lewis] enjoys [the social part] of his job the most. He thrives on interactions with other at work." (Employer L)

2. Personal enjoyment
3. Financial gains

The benefits for the employer of employing individuals who use AAC included:

1. Personal inspiration
2. Positive effect on other employees

"Because of Alan's extremely difficult physical situation, he truly provides motivation to those around him. Because of his 'can do' attitude, others around him are impacted to recognize how good they have it in life." (Employer B)

3. High quality work performance by employee
4. Loyalty of employee

"He needed to be somewhere the next morning, and he had (been having) some trouble with the paratransit, which was always a problem. He slept on the floor here (at the office), so he could be here (on time). So, the motivation is extraordinary and I do respect that." (Employer K)

5. Ability of employee to work in a "hard to fill" position

The benefits to the general public by employing individuals who use AAC included:

1. Abandonment of stereotypes

"[Hiring Isaac] sends a strong, positive message that people with severe disabilities can function and contribute to the work place. I think it has opened many people's eyes to what technology can do to improve life for people who have a disability." (Employer I)

2. Increased awareness of AAC
3. Visible positive role models for other individuals who use AAC

Challenges to employment included:

1. Challenges finding a good job match
2. Challenges with communication

"Waiting for her to explain and try to demonstrate the problem requires enormous patience. Things will take much longer. And you tend to get antsy, like 'come on, get the next word,' but you can't do that when they have to go through a long process [of inputting into the device]. So it was just something that was really a big problem." (Employer G)

3. Challenges with accessing traditional office tasks
4. Challenges with education or vocational skills level

"Determining what they really know, and their true education level (is challenging). You quickly learn that 'graduated high school' may not have (any real) meaning....You're likely to find out things that are going to surprise you considerably from the reports you get from the case workers and OVR, that indicate the person's education level." (Employer G)

5. Lack of knowledge of traditional work culture
6. Physical challenges
7. Need for assistance from others
8. Challenges with accessibility
9. Financial challenges

Supports to employment included:

1. Supports to communication
2. Supports to accessing traditional office tasks and activities

"I tend to talk kind of fast and unload things on people. I almost insist that people have a pen and paper and write down what I say so I don't have to repeat myself. I found what I would do is explain things to Neil, then I would always follow up with a short written memo of what we had talked about so that he would have it." (Employer N)

3. Supports to educational or vocational skill level
4. Personal care assistance
5. Accessibility supports

"I had a presentation that [Kevin] was participating in and he was in a major state conference and I had a panel of AAC users. There was a huge snowstorm. Well, wheelchairs and snow don't go well together. We had to prepare for this. We had everyone hooked up by speaker phone." (Employer K)

6. Personal commitment of the employer and co-workers

"I had worked with the blind, the visually handicapped, for 7 to 8 years at that point and I thought I had solved a lot of problems...this person [Gina] can actually type words into a computer using that system and I said, 'Gee, I could put this person to work' and I (felt) very positive at that point." (Employer G)

Recommendations for improving employment outcomes included:

1. Recommendations technology manufacturers
2. Recommendations to government

" [Government should] recognize that there may be additional expenses. I can see that going into the business world and saying that this person needs personal assistance services [might be hard], but yet, all of us need assistance....So, it's really broadening our notion of ... how people are really interdependent." (Employer K)

3. Recommendations to employers

" Walk around with the AAC user a couple of times the first few days...Introduce him and model how to interact with him; for example, pausing, waiting for responses...the idea should be preemptive and proactive to forestall communication breakdowns." (Employer E)

4. Recommendations to individuals who use AAC

"We KNOW paratransit is not going to show up, and we KNOW that personal assistants are not going to show up, and we KNOW your device is going to break down. So, what's your back-up to that? If someone is going to do a presentation to one of our classes on assistive technology, I don't want the excuse, 'Oh gee, the device broke.' Have a back up. These are the realities and they will happen." (Employer K)

5. Recommendations to professionals in the field of AAC

Further research still needs to be completed to gather more information on the opinions and perceptions of employers and co-workers who work with individuals who use AAC. In addition, more research on the perspectives of the individuals who use AAC would be very helpful. Finally, there is a need for a means to evaluate intervention programs that are designed to address the concerns of employers and for research in the development of effective school-to-work transition programs.

SUMMARY

The results of the present study provides evidence of many ways that companies, individuals who use AAC, and society as a whole can benefit from the employment of individuals who use AAC. In order for these benefits to be realized, however, the proper supports and a willingness to collaborate must be in place. There clearly is a need for structural change to address the challenges of educational preparation, technology integration, transportation, and personal care assistance described in this project.

Perhaps more important than any specific legislation or technology, however, is the belief that hiring an individual who uses AAC can provide tangible benefits in the workplace, and that the extra effort to provide needed accommodations is time well spent. In describing the employment experiences of 15 individuals with disabilities, Ochocka et al. (1994) commented that "the key accommodation (to support successful employment) was an attitude among co-workers and employers that it was important to pay attention to the individuals' needs...(and to) accept accommodations as a natural part of the work experience" (p. 47). The experiences of the individuals in the present study were very similar - the combined efforts of the 14 employers and co-workers, as well as the 10 individuals who used AAC, resulted in employment benefits for all.

FOR MORE INFORMATION:

David McNaughton, 227 CEDAR, Department of Educational and School Psychology and Special Education, The Pennsylvania State University, University Park, Pennsylvania, USA. dbm2@psu.edu.

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Town Meeting—Topic: Strategies and Partners in Employment Speaker of the House: Randy Kitch, B.S.

Kim Vuong, Los Angeles, California

Hi my name is Kimberly Vuong. My speech is about myself, and my experience using an AAC device in a nonprofit workplace. I started out working for UCP as a computer coach. They were very patient, even though I didn't have a communication device at that time. They were used to people with speech impairments. Then the Dayle McIntosh Center offered me the job of Assistive Technology Researcher Specialist. Soon my boss told me that my consumers didn't understand me in person or on the phone. I worked very hard to get a device. I first went through my insurance and they sent me to a speech language pathologist who knew nothing about AAC. I learned that there are not many speech pathologists familiar with AAC. I didn't want to go back to my doctor to get another authorization for an evaluation from another regular speech pathologist. So, I called my department of rehabilitation counselor and told him that I wanted to meet with him to talk about getting an AAC evaluation. It took a month for the department of rehabilitation to send me to a local evaluation center. ATEC is the only evaluation center in Orange County. The department of rehabilitation took six months to authorize my communication device. They gave me only 10 hours of training time on the device. I think that 10 hours of training is not enough to be good with our devices. It took me

several months to learn how to use my device in person and on the phone. I use my device and speech-to-speech telephone service when I am on the phone. I use my device when I meet new people at work. I also use my device when I go to meetings at the regional center. I am currently co chair on a committee that is planning to get an AAC support group and conference going in California. According to a study, less than 10 percent of AAC users are employed in the u s? RESNA did a study and found that AAC users cannot afford to lose their government benefits, and many others don't have the education that they need to get a good job, or get a promotion. Education is needed for AAC users to get and keep jobs. Thank you for your time and attention.

Marriage and Employment: Domestic Life

Randy & Brenda Kitch

Kim Vuong

Anthony Robertson

Randy & Kimberly Horton

Kate May & Juan Gonzalez

Rick & Irene Hohn

Working in Technical Service and Training for a Computer Company

Anthony Arnold

Jane Burgan

David Chapple, B.S.

Bac Shelton, B.A.

Preview of the University of Dortmund Project

Andreas Seiler-Kesselheim

Working in Politics

Ryan Duncanwood

Tiffany Adams

Randy Horton

Unexpected Uses of AAC Technology for Employment

Sue Rubin & Rita Rubin

Background to my voice- Facilitated Communication-

Before the age of thirteen I was thought to be mentally retarded. Then I was introduced to Facilitated communication, which has become my only way of expressing my thoughts. It is in every sense of the word my voice. Without it, I would not be able to be a functional thinking individual. Without facilitated communication, I would not be able to assert my wants and needs as small as they may be. Before FC I was only capable of showing my wants and needs by aggressive, unintelligible behavior: I would scream, kick, bite and scratch to let someone know I did not want or like something, but it was up to the individual to figure out what was actually bothering me. With FC being introduced to me I was able to for the first time explain what was actually on my mind, without

having to hope that someday people would understand that the reason I was exhibiting ghastly behaviors was not to frighten, but to convey a message.

Preparing for work as an undergraduate university student-

The transition from high school to college was definitely a life changing experience. It was the biggest monumental change to adulthood I have encountered thus far. Being placed in higher academic course work through high school via Honors and Advanced placement classes helped prepare me for the content and work load a freshman in college would have to face. There were trials and tribulations that I faced being in an inclusion setting with peers of my own academic capabilities. At first I was not able to sit in the classroom for more than five minutes without exhibiting horrible behaviors, I was soon able to become more familiar and comfortable with my setting and my awful behavior subsided. That does not mean that on a bad day or without notice to anyone it would not rear its ugly head.

The eye opening experience of high school-

This was the first time in my life I was truly challenged and held accountable for the hopes and dreams I wanted to pursue. I had to prove that though autistic I have been blessed with an amazing mind, one that has the potential to move one day on to graduate standing, but the road ahead was not easy. In high school I was faced with the complexities of sitting in an autistic body, which does not listen to my above average mind, and sit and do my studies for three to four hours daily. This was painstaking and at times trivial though I persevered with the aid of my mother at my side.

The easiest part of the college experience as some may know is getting in. At first it feels as if the testing and records will eat you alive, but there is no better sense of accomplishment and fright than finally receiving the white envelope that holds the key to your future. I knew that within that envelope lay many a transition to the future.

Transitioning to college-

The first thought any college student is faced with is where they will reside while attending school. Though dorm life is the freedom that every freshman desires I knew early on that it would be unrealistic for my situation. Though I had much maturing to conquer I knew that having a roommate was out of the question, as well as living in the obnoxious surroundings of other freshman. How would I explain my idiosyncratic behaviors such as banging my head against a wall when frustrated, or screaming at the top of my lungs when my body language seems to be relatively normal? I couldn't. Living in the dorms was entirely out of the question. My parents and I decided instead that I would live off campus in my own home with a roommate. To shorten a complicated story the roommate didn't last long, but I have been living in my own home away from my parents ever since beginning college.

Support staff-

Living on my own has been a great deal of work. I had to find support staff for not only my academic life, but also my social one as well. These individuals have become the first true friends I have ever made. Being my support staff the individuals first had to believe that I was capable of doing college work and they had to believe that they could support me in an academic environment.

My accommodations-

Due to autism I cannot use a verbal voice. I discovered a technique called Facilitated Communication that enables me to type on a keyboard. It can take a great deal of time to produce even a paragraph. I must have the physical reinforcement of my staff by me at all times during class. Their physical body must be close to mine to alleviate tension that I am feeling. I sit now through lectures up to two hours; where as when I began school I had a difficult time sitting in a chair for five minutes. When I first began typing I needed physical support on my hand and gradually faded back to the top of my shoulder. This took approximately two years to overcome. I am now able to type completely independently, without touch, with staff that I have a close connection to. My support staff that accompany me to school must take notes for me as a form of accommodation, as well as situate me in a "sensory friendly" environment. Autism is attacked by sensory overload, and my body reacts to the smallest of sensory distractions, such as a car going by an open window, the sound and the visual stimulation can set me into a frenzy. My keyboard must be light and portable so that I am able to do work independently without the support. I several different devices from a computer keyboard for long papers to small portable keypads I can carry in a purse.

Reliability-

I can assure skeptics that I am held accountable for my own academic work, and must do all of the work on my own. The staff I have has been well trained mainly through their own college experiences to know what work and standards I must adhere to.

Where I am now-

My academic road has not been an always-easy one, but it has been a journey well traveled. I am now a junior, majoring in History celebrating summer break. My goals are simple; I want to graduate from college. It may take some time, but it will be well worth the hard work. I have been taking only a class a semester due to the workload upper division classes require. I am also involved in many organizations and am a board member on many committees. I am sure that someday-graduate school may be something I challenge myself with, as for now college is plenty of work.

Being an AAC Advocate

Bac Shelton (Panel Chair)
Leigh Ann Lightholder
Donald Jones, B.S.
Ray Peloquin **Sara Pyszka**
Paul Garrick **Kyle Glozier**

RERC Projects Benefit the AAC User:
Communication Disability Employment and Social Networks
Blyden Potts, M.A., Allison Carey, Ph.D., CONTACT _Con-466ACC3FF3 \c \s \d
Diane Bryen, Ph.D.,
Kevin Cohen, M.S., CCC-SLP

Tell Me About It: Communication At Work
Susan Balandin, Ph.D.

Author's Index

The author acknowledges the editing contribution of Susan Balandin. For further information contact David Trembath, 12 Oleander Pde, Caringbah NSW 2229, Australia. Email:dtre2817@usyd.edu.au

PEC@ 8th Annual Conference Pittsburgh, Pennsylvania 2001 PAGE 14

PAGE 15