Proceedings

of the

Biennial

Pittsburgh Employment Conference
for Augmented Communicators

PEC@ '05

August 5-7, 2005

Sheraton Hotel
Station Square
Pittsburgh, Pennsylvania
USA

SHOUT PRESS

PREFACE

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Executive Director

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The Theme of PEC@ 2005
"Employment and Community Interaction"

Jennifer Lowe
Executive Director, SHOUT

As the Executive Director of SHOUT, it's my privilege to welcome you, to the 2005 Pittsburgh Employment Conference! The theme of this year's PEC is Employment and Community Interaction. People interact in the community & in their employment, all the time. It isn't any different for an augmented communicator, than it is for an, able bodied person. Isn't that great? The only difference is it may take time for an augmented communicator's colleagues to acclimate. They have to learn that they have to wait for their colleague to talk. Also, they have to get beyond the device to see that their colleague, who uses a communication device, is just like them, mentally, spiritually, and so on. This may take some effort. From my own experience, I have learned that this was true.

When I first started to work at my work place, my colleagues didn't, quite, understand how to have a conversation with me. Fortunately, they did have some experience with an augmented communicator because, another worker there, also relied on an augmentative communication device. Therefore, they weren't, totally new, to this experience. However, I did get exasperated with them, in the very beginning, because, they would ask my support person, questions, that they should have directed, to me. Admittedly, I shouldn't have done that. However, the fact that they worked within the Special education field, and, work with another person who relied on an AAC device, I had higher expectations of them. It didn't take them very long to acclimate to me & the way I communicated. As I recall, it took them approximately, a month, for my colleagues to acclimate. They learned that they had to wait for my response. Of course, it did help that I had the strategy of leaving the speech on, as I composed my sentences. Now, I interact with my colleagues with no difficulty at all. I laugh, joke, & relate to them as I have known them all my life.

Interacting out and in the community, have its challenges for an augmented communicator too. Although society has learned more about people with disabilities, it isn't where it should be. People still automatically assume certain things about me, as an acuminated communicator. You all know them. First, they assume that I am deaf. Guys, I don't know about you, but, sometimes that really challenges my patience! Second, people assume I don't understand what is going on in the world; like I am in a world of my own. Even though, I may react to them like anyone else does. Finally, people still have trouble with comprehending that I have the same goals as they have, and it isn't meant to be courageous or inspirational. I want to, one day have a family. Yes, that's a nice goal, but, it isn't meant to be inspirational. Several able-bodied people have the same goal and, they aren't viewed to be inspirational.

When I'm out, and, in the community, it's still challenging for me to communicate with people who I haven't spoken to before. It's fortunately improving, with awareness. When I am presented with this challenge, I choose to look at it as a teaching opportunity. I realize that not everyone views this frustrating experience, to be a teaching opportunity, but, differences make the world

go round. Right? I would much rather look at this frustrating experience as an opportunity to educate, rather than, condemn. How I accomplish this, is by, asking people if they have any questions, about me, or, about my communication device. Generally, they do ask questions. Doing this, solicits a positive response. They smile, or, say wow; like they are simply amazed that I could explain my device. Then, I just smile, and go on my way.

Communicating in the community is often challenging for me, as an augmented communicator, because, people just may not know how to approach me, since I have an augmentative communication device. There are people with a; a; c, who have poor attitudes. People may have attempted to talk to such an individual, only to get a negative response. That may just have prevented this person from attempting, again, to initiate a conversation. Another reason may be, simply that they may not want to offend me, the augmented communicator. Still, another reason may be that I, being the AAC device, user, may be slower in talking than they are used to. Let's face it, this world is getting more and more, fast paced. I do realize, being an Augmented communicator, that I do talk slower which requires the person that I am talking with, to have a little more patience. These are just some of the reasons why community interactions are frequently difficult for me as an AAC user. As I sit here, I'm sure that every AAC, user, can identify with that.

As I said, this year's conference theme's focus, is, Employment & Community Interaction. The presentations that you will hear will deal with different aspects. To illustrate this, I'm going to preview three presentations. Sarah Lever will share her difficulties traveling. In her presentation, she went into some very personal and intimate details about her traveling which will encourage you to learn the rules of flying. Anthony Arnold explains the challenges he experienced along with his parents and how he overcame them, in his presentation. He also explains how he gained work experience and ultimately, his job now. Brown Hemsley, Susan Balandin & Leigh Anne together will explore the issue of going into the hospital, from an AAC users perspective. In this presentation, they will outline the people who AAC, users will come across, who they will need to talk with, & suggest ways of how they can prepare. Other presentations will include; What every OVR counselor should know about how to serve a Client who uses AAC, by Robert Stump & Jim Prentice. Serving & being served: a VR counselor & VR consumer tell their stories, by Gary Donatelli & Don Jones. Community Interactions: a; a; c & being a church member, by Dennis Hollman. How valuable is voice output for employment, by Randy Kitch and Bruce Baker. Getting Children who Use AAC, Ready for the real world & getting the world ready for them, by Robin Hurd.

With no further ado, let the 2005 Pittsburgh Employment Conference begin!

PEC@ 2005
Employment and Community Interactions

Platform Presentations

Community Interaction: A Recipe for Success

Susan Balandin, The University of Sydney

Active participation in the community is a key to a good quality of life. People interact and participate with their community in many ways, working, volunteering, being involved in sports, social clubs, or religious organisations. Indeed it can be argued that any activity that happens in the community results in an interaction. Yet, people who use augmentative and alternative communication and those who support them have noted that living in the community does not in itself ensure community participation or integration. Thus, there has been criticism that people with disability may live in but not be part of the community. In this presentation a range of issues that impact on successful community interactions will be discussed. Drawing on recent research some of the opportunities for and barriers to successful community interactions will be explored, including the impact of employment, leisure, health, loneliness, and the expectations of both communication partners. The aim of this presentation is to encourage the audience to consider community interaction in the broadest sense and to challenge any notion that partner training is the only recipe for success.

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What Every OVR Counselor Should Know About
How To Serve a Customer who uses AAC – From Intake to 26!

Robert T. Stump

The incidence of conditions which render people unable to speak, or unable to be understood by others is fairly high. One estimate reveals that one in four families include members who are unable to speak for a significant period of time. Many of these people acquire non-speaking status late in life, and are not candidates for employment. In the vocational rehabilitation arena non-speaking people have represented a low incidence disability. There are, however, an increasing number of such persons who wish to enter or continue in the work force. These benefit by using devices with computer based speech for more effective communication.

This presentation will provide information to assist rehabilitation counselors serving persons who can use Augmentative and Alternative Communication (AAC) devices. Strategies will be suggested for meeting and considering plans and services with these customers.

The discussion will include:

Etiologies of some severe speech disorders
Congenital conditions
Acquired speech disabilities

Strategies for becoming a more effective communication partner with augmented communicators
Common problems of individuals who use AAC
Characteristics of communication partners
Habits in language style that sabotage effective dialogue
Pausing

The role of the rehabilitation counselor
The initial interview
Eligibility determination
Specialized services that may be needed
Exploring job possibilities

James Prentice --PAPER

What you Tell – and What you Don't Tell – Your OVR Counselor at the Beginning and Throughout Your Relationship
Jennifer Lowe
Executive Director, SHOUT

Dealing with an Office of Vocational Rehabilitation counselor can be complicated. I was asked to present the do's & don'ts of talking to your OVR counselor. I'm here to tell you, that it isn't cut & dry. To be honest, I am not an expert & learned as I grew. In this presentation, I'm going to illustrate what I have learned. It's important that you understand, that it would change with each individual and, each OVR counselor.

Do; tell your OVR counselor your ultimate job. Do; know your capabilities and your passions, because, perhaps, one of those passions could become your job. Do not be unwilling to hear other options that your counselor may have. Do, know yourself. This also includes, knowing your limitations. Don't make your OVR counselor your enemy.

When you initially recognize that it's time to pursue employment, you have to dream, of your ultimate job, and you should articulate your dream to your OVR counselor. My ultimate job was helping augmentative communication users with their communication devices. I desired to help them improve their communication skills. When I encouraged a new user, and I observed that they expressed their thoughts, needs, desires and so on, a feeling of accomplishment & hope came over me. I would, feel, so, good! That's how your ultimate job should make you feel. For years, I described my ultimate job to my OVR counselor. This was good to do, although I admit, I feared that I sounded like a broken record, sometimes. At least, my counselor knew what my dream employment situation would be. That was good because, he knew what direction that I wanted to go and had some idea of how to assist me.

I'm going to sound kind of contradictory, here, but hear me out. Before I said, don't be willing to compromise on your ultimate job. I am going to say that, you should be flexible, in the kind of job that you pursue. If you desire to be a singer, and are non-speaking, you shouldn't expect that you will be a singer. That's just being realistic. That's also called knowing your limitations.

With me, I have always desired to be a teacher. However, pursuing a teaching job wasn't so realistic for me. I did recognize that. From time to time, I do teach. I accomplished this, through delivering presentations. Several college professors have requested me to speak, or, teach, about my disability and communication. One presentation that I did, for Katherine garret, provided an opportunity for me to teach. I absolutely loved it! It fulfilled a dream of mine. Though I am not a teacher per say, I have taught. Don't go against your OVR counselor's wishes too much. Here is what I mean.

As I was pursuing employment, I kept in mind what my counselor required of me, in order to keep him working with me. The ultimate stipulation was for me to work at least, 11 hours a week. This took years for me to accomplish. Then finally, I did accomplish this. In fact, I work for an organization called PaTTAN for 12 hours a week, now. PaTTAN is the acronym for; Pennsylvania Training and Technical Assistance Network. It's affiliated with the Intermediate Unit 1, within the special education school system. Gaining this position at PaTTAN fulfilled one of my OVR counselor's stipulations to have him continue working with me.

Don't make your OVR counselor your enemy. Instead, you want to establish a good rapport with your counselor. In my case, that was what I did, and, it proved to work rather well. Since I had this rapport with him, I felt comfortable going to him with my issues. While I was at Edinboro University earning my degree, my counselor changed due a job move. What made this a challenge was that I considered this counselor to be my friend. I still do, & remain in contact with my initial counselor.   I'm pleased to say that I managed to establish a similar rapport with my second OVR counselor. That has made working with him easier and ultimately more productive.

Just like any kind of relationship, the relationship that you have with your OVR counselor takes work & a lot of commitment. It evolves through time like I have illustrated through my experiences. I have no qualms in saying that my relationship with my counselor may evolve even more. In fact, it's inevitable that my relationship with him will. That's life. Be willing to put every effort into making the relationship with your OVR counselor work. As you can see through mine, it was to my advantage, because, it made my relationship be a success!

Dave Bostick – paper

David L Bostick CRC LPC M.Ed.
Vocational Rehabilitation Supervisor, Pittsburgh District Office
PA Office of Vocational Rehabilitation

Don Jones -- Paper
Don Jones, B.A., Board of Directors, United Cerebral Palsy of Pittsburgh

Snoopi Botten

When communicating with anyone, it's important to remember that your communication device is only an aid. It might be out in front of you so you can access it and so people can hear what is coming out of the speakers, but you need to project yourself in front of the device and reflect what is being said.

As a long time user, I have had to work hard at jumping in front of my own device and myself be an amplification of what is being spoken. Although I am still not as far as I want to be, I hope these suggestions will help you as you interact with other people.

1. When having a casual conversation, have the Language Activity Monitor (LAM) turned on to record your end of the conversation. Later, review your vocabulary during the conversation and see if you can change how you access core vocabulary for faster access.

2. While using your device to communicate, try to make eye contact with the person or people you are talking to. Looking at the device the entire time you are generating what you want to say makes people lose interest in what is being said. Making eye contact and facial expressions helps to stress what you are saying

3. If you are going to be speaking to a large number of people and you know what you will be saying a head of time pre-program it. As you preprogram, think about what you could be doing along with the talk. What movements you want to make, what props you want to show, and how long you want to give the audience to respond. As you prepare your talk, don't program the entire talk all at once. Rather, program it in sections. This makes it easy to edit each section and practice what you will be doing as the device is talking. Then program the next section, edit it, then practice from the top before programming the next section. It gets old, but it makes actions and props become automatic.

4. When talking one on one with someone, especially to a person you just met, try to keep your responses short and not self centered. People are scared enough if they have never dealt with a disabled person, so having to wait for a long response may make them uncomfortable and walk away. Having a pre-programmed statement explaining how it might take you some time to respond will help the situation.

5. Try to use comedy in your talks. Comedy is such a great way to break the ice and get people to laugh at certain situations. The comedy has to flow together. If a joke takes too much explanation to make the punch line funny, don't use it unless it's a big set up for a series of jokes or puns. And always allow a minimum of 2 seconds for people to laugh. If you expect a joke to be very funny, allow up to 5 seconds for laughter.

6. Before engaging in a conversation or speech, check and ask if your volume level is set appropriately. Every environment is different; the size of the room, the number of people you are talking to, the sound system, and even the weather. So always ask if people can hear you before you start speaking.

7. Be ready for anything to go wrong and be very fast with a joke. For some reason there are times when anything that can go wrong will go wrong. In these times you've just got to make the best of it. You may want to pre-program some clever stuff for those

times when things do go wrong. If you can handle a bad situation, that's what people will remember.

I hope this will be helpful to you. All of these are only suggestions. As you go through life you may find other things to help you jump in front of your communication device. Good luck.

How ACC, With All Its Challenges, Fits Into The Rehabilitation Vision

John L. Bernard
President, SHOUT

PA OFFICE VOCATIONAL REHABILITATION (OVR) VISION:
Through our actions, we shall earn and maintain the highest degree of respect from our customers and be viewed by them as a world-class organization.

PA OFFICE VOCATIONAL REHABILITATION (OVR) VALUES:
Accountability
Continuous Improvement
Customer Satisfaction
Effective Use of Resources
Employees
Equitable and Just Treatment
Partnerships
Professionalism
Teamwork

ASSURANCE OF HIGH LEVEL SERVICES TO AAC CUSTOMERS
Staff Development & Training
Personnel Standards for OVR Counselors
Independence Capital Access Network
Supported Employment/Job Coaching
Ticket to Work Program
Transition from School to Work
VR Reimbursement Program/Social Security

HOW LARGE IS PA OVR STAFF:
15 District Offices
700 Employees

    400 VR Counselors

BUREAU OF BLINDNESS & VISUAL SERVICES

PA'S ASSISTIVE TECHNOLOGY LENDING LIBRARY

HIRAM G. ANDREWS CENTER

ROBERT WATSON – PAPER DUE

So You Want to Work?

Some Lessons Learned from Five Years of Work with the RERC[1]

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It is no longer news that people who rely on augmentative and alternative communication (AAC) have extremely low rates of employment (at best 15%), only about half the rate of employment for all persons with disabilities in the United States (Blackstone, 1993; Harris Survey, 2000; U.S. Census Bureau [SIPP], 1997). The alarmingly low rate of employment exists regardless of level of education. Access to communication and related assistive technologies; entitlement to a free and appropriate public education guaranteed under IDEA; availability of workplace accommodations; anti-discrimination legislation (e.g., Title I of the Americans with Disabilities Act, Section 508 of the Rehabilitation Act); and use of powered mobility devices should substantially offset the impact of communication and mobility disability in the workplace.

Research has provided a "menu of barriers" faced by individuals who rely on AAC in finding employment, among them: (1) poor work preparation, (2) lack of needed literacy and math skills, (3) financial disincentives to work, (4) few opportunities to hold first jobs as young adults, and (5) physical, environmental, and attitudinal barriers. In addition, despite increasingly flexible and powerful AAC technology, current communication technologies still have limited capabilities and reliability when compared to the natural voice of persons without communication disabilities.

Employment programs have attempted to address high rates of unemployment through solutions that address both the supply and demand sides of the problem. On the demand side, programs focus on overcoming stereotypes, encouraging employers to hire persons with disabilities, and developing workplace accommodations. On the supply side, programs focus on offsetting human capital deficiency (e.g. lack of skills, ability, and knowledge) through education and job training.

Recognizing the importance of employment for individuals who have significant physical and speech disabilities, the National Institute on Disability and Rehabilitation Research (NIDRR) established employment as a priority in 1998 when this agency issued a request for proposals to establish a Rehabilitation Engineering Research Center on Communication Enhancement.   Since its original funding in 1999, colleagues at Temple University as well as those at Penn State University have begun to address this priority from a variety of perspectives and strategies. The purpose of this paper is to summarize the lessons that we, at Temple University, have learned from approximately five years of work on employment and people who rely on AAC. These lessons should have relevance to people who rely on AAC, employers, vocational rehabilitation counselors, educators, manufacturers, and researchers.

The lessons learned presented in this paper are based on five years of participatory action research focusing on improving employment outcomes through a *ACETS – Augmentative Communication Employment and Training Supports* resulting in two published articles and a newly published training guide. Other lessons learned are drawn from a series of research studies conducted by the Temple University team focusing on human and social capital, technology, and structural gaps. The citations for this research are found at the end of this paper.

Lessons learned are based on the model of *human and social capital*. At its core, the *human capital* model addresses the question of whether the job applicant is qualified to fill available job opportunities (i.e., does the applicant have the needed skills, knowledge or abilities to perform the essential functions of the job), This model assumes that information about job opportunities is available to the interested and qualified applicant. The *social capital* model addresses how available the job seeker is to the job opportunities that he or she is qualified to fill. Research conducted at Temple University was based on applying both the human capital and the social capital models in attempts to improve the employability of persons who rely on AAC.

The information presented in this paper based on the experiences and input from approximately 45 persons who rely on AAC – some employed and some unemployed but interested in becoming employed. In addition, information was

obtained from 10 "matched individuals without disabilities," and 20 employers. Two instruments specifically developed for these studies - *ACETS Employment Survey* and *Employer Network Survey* were used. Information about the content, development, and reliability of each instrument can be found in the original studies cited at the end of this paper.

Lesson 1: The Importance of *Human Capital* in Getting a Job

Human capital – which is skills, knowledge, and abilities, are needed to get a job. They are necessary conditions but certainly not sufficient conditions for becoming employed. Let's take a look at some of these skills.

Nearly all jobs require an *interview*, including one or more in-person interviews. Employers that we studied generally did not allow substitute interview methods (e.g. via email, instant messaging) for a personal interview, and only half would allow a job applicant who relies on AAC to receive most or all of the interview questions in advance. This can place a job seeker who relies on AAC at a competitive disadvantage in the hiring process regardless of skill in using one's AAC device. Where alternative media are available or questions can be provided prior to the interview, interviewees who rely on AAC should prepare themselves to make best advantage of the opportunity. Where such policies are not yet implemented, interviewees who rely on AAC might want to inquire if such an accommodation can be made for them. Whether such an accommodation is possible or not, active job seekers who rely on AAC should strive to anticipate the questions they will receive and have prepared answers for anticipated interview questions. Several websites exist that may prove useful in that they provide the most commonly used interview questions thus enabling the individual to prepare responses in advance (c.f. http// www.quintcareers.com/interview_question_database/)

Employers should consider their interview policies carefully. Are oral/spoken communication skills an essential function of the job? If not, consider options such as giving the interviewee who relies on AAC the questions in advance, or interview via email instant messenger, or other computer "chat" options.

 Obtaining *job references* is another important job searching skill since almost all of the job types required references. Job seekers who rely on AAC should request and have identified several good references to rely on for any job application. Individuals who have limited options for job references because they have little work history should actively cultivate references from other sources, such as former teachers, supervisors from volunteer experiences, or known clergy.

 What is entirely expected and strongly reinforced by our findings is the importance of *hard skills*. Based on the Department of Labor's Futurework analysis, "American does not face a worker shortage, but rather a skills shortage. The employers in our study consistently stressed the importance of *communication skills* and "standard voice" as job requirements for the overwhelming majority of jobs. These skill requirements present an obvious challenge for individuals with significant communication disabilities who rely on a nonstandard synthesized voice, and are frequently cited by employers in our study as a key challenge to employing persons who rely AAC. The frequency with which limitations of AAC technology (i.e. failure of the technology to compensate for the disability in intelligibility, rate, and reliability) are mentioned as a barrier lends further support to the importance of this obstacle, and reaffirms the conclusions of prior research on the importance placed on knowing how to use the technology, having the technology well-prepared for workplace communication, and having technology that is reliable.

 Another finding of importance to both educators and individuals who rely on AAC is the breadth of jobs which require and emphasize *strong time management* skills. Time management skills are a requirement of many of the job clusters including most of those that include jobs that AAC users often desire. Time management, *problem solving* skills, *fit with workplace culture*, and *co-worker relationships* may be the hidden human capital barriers to employment. Each of these is a key skill requirement of a number of jobs including those commonly listed as desirable by AAC users and at least occasionally mentioned as a specific challenge facing employees who rely on AAC. Furthermore, time management and problem solving skills have been identified by the Department of Labor as key skills that will be needed for many jobs in the 21st century.

Finally, *technology requirements* of jobs were also not surprising and once again are consonant with the findings from the Department of Labor. Though few of these jobs require highly specialized technological skills, the vast majority of jobs required the ability to use a telephone, computer (e.g. email, Internet, word processing), and copy machine. The technology revolution has not only affected future jobs but current ones as well. Even workers in "non-tech" jobs must have some technological know-how, such as the use of word processing programs, multi-line telephones, and use of the Internet.

So if you are an individual who relies on AAC and you want to work, or you are an educator preparing individuals for competitive employment, or vocational counselors, the findings from these 20 employers should be quite helpful. First, while educational credentials are always important for finding a job and improving one's career opportunities, developing skills through nontraditional means may also be helpful. Skills are the key to meeting the job requirements of many employers and for many jobs.   Beyond math and literacy skills, employers are looking for employees who have good communication, time management, problem solving, and technology skills.   Whether they are developed in traditional educational settings, such as high school or college, or in nontraditional settings, such as technical schools or on-the-job training, the important message is that these skill be developed.

Finally, the results from these studies have much to offer manufacturers of AAC devices. Employers in this study are suggesting that if AAC devices are to promote socially-valued roles for adults, including employment, then the devices must have a more standard-sounding voice and must be reliable.

Several additional recommendations for changes in policy and practice have emerged from our studies. First, and foremost, the expectation for employment must begin early – both at home and in school. Despite far-reaching civil rights legislation (i.e., IDEA, Sections 504 and 508 of the Rehabilitation Act, and the ADA), individuals with significant disabilities continue to face low expectations, lack of access to the digital highway along with other marketable "hard skills," and limited opportunities for career exploration and work experience while in school. In fact, when asked, "When did someone first ask you what you wanted to be when you

grew up," all ACETS participants replied that "no one ever asked me." Schools must do a much better job in providing the education, training, experiences and expectation needed for school to work success.

Similarly, results from our work have much to offer vocational rehabilitation (VR) counselors who are charged with enhancing the employment outcomes of persons with the most significant disabilities. Counselors might make note of the innovative use of information technologies, such as email, on-line charting of progress, and teleconferencing used during our ACETS training activities and all of our research. These types of technologies appeared to be effective for maintaining the participants' motivation, keeping participants focused on their goals, providing feedback, and remaining in contact with staff despite large geographical distance. Vocational rehabilitation professionals might consider using these technologies as an effective and cost efficient method for providing services to people who use AAC as well as other clients who might live in rural areas of the country. Successful employment strategies used with other populations, such as job carving, job coaching and supported employment strategies also have much to offer people who rely on AAC.

Our work has demonstrated that human capital is important for employment. *Human capital* can and should be taught. However, human capital is not enough!

Lesson 2. The Importance of Social Capital

During the past two decades, a growing body of literature has shown the importance of *social capital* in finding jobs. However, social capital has received little attention among those concerned with the employment of persons with disabilities. There is a tradition of identifying family, friends, and coworkers as potential sources of "natural" social support for workers with a disability or less often as potential employment contacts, but the concept of social capital as a key to employment success has otherwise been largely ignored among those assisting persons with disabilities to find employment.

While *human capital* focuses on skills needed to obtain and maintain a job, *social capital* addresses social networks needed to get a job that the candidate is

qualified for. Many researchers have shown that social networks are fundamental to finding jobs, and to finding *better* jobs. Though percentages vary by type of work, from 40% to as high as 70% of persons find their jobs through contact persons in their social network. The networking adage "it's not <u>what</u> you know but [also] <u>who</u> you know," has given rise to a wave of books advising people on how to tap their social networks. Our research has underscored the need to address *social capital*, especially given our findings that individuals who rely on AAC have small and redundant social networks. This is especially true of those individuals who are unemployed.

Educators and vocational rehabilitation counselors might want to help students and job seekers who rely on AAC find answers not just to the question "How do I get qualified for available jobs?" but also "How do I become known to employers in jobs that I am qualified to fill?" Vocational counselors can benefit from a basic understanding of social network analysis that can provide them with conceptual tools to help their consumers take a social capital inventory, target directions in which to build their social networks, and reduce network redundancy. Counselors need to steer job seekers away from building networks that draw too heavily on a limited number of social contexts (e.g. family, coworkers) and toward networks drawn from more diverse contexts. Existing strategies that build job contact networks, such as job shadowing and internships, should be encouraged. Vocational counseling programs should incorporate components that explicitly address the "where", "who", and "how" of meeting people and maintaining social relationships that might lead to possible job opportunities.

Individuals who use AAC might build job contact networks through volunteering and participating in clubs, civic and religious groups, and other social activities, with an eye toward the size and diversity of their networks and the jobs they desire. Job seekers need to present themselves in ways that cause their contacts to think of them as potential applicants for job opportunities. Meeting new people is a primary goal, particularly people who are not already known by somebody the AAC user already knows. Advice on how to do this, most of which is as appropriate for persons who rely on AAC as it is for the general population, is available in numerous books on "networking". Job hunters who rely on AAC should

keep in mind that persons they already know who they may not think of as job contacts may sometimes serve in that capacity.

Lesson 3. The Importance of Generic Communication Technologies

Access to and the use of generic communication technologies, especially the Internet, email, and cell phones, are important tools for developing, using, expanding, and maintaining job-related social networks. They may be particularly essential for individuals who rely on AAC, given today's highly information-rich society. Not only do these technologies reduce social isolation and increase social networks for a population that may find travel and face-to-face contact difficult, but they also increase access, anywhere and at any time, to information. These and other benefits are underscored by the findings of the Rehabilitation Engineering Research Center (RERC) Technology Transfer Demand- Pull Forum in 2001 where it was suggested that communication technologies such as cell phones and the Internet allow people who rely on AAC to break out of their physical limitations and expand employment, educational, and recreational opportunities.

Lesson 4: Reducing Structural Gaps.

Are job seekers who rely on AAC and potential employers separated from each other by a structural hole? The answer is mixed. With respect to employers in the field of AAC services the answer is a resounding "no". As a group, job seekers who rely on AAC appear well connected to these employers, although these potential employers are quite limited in the number and type of jobs available. With respect to other employers in our sample of 20, there appears to be a nearly complete lack of connection between potential employers and potential employees who use AAC. In other words, there is a definite structural hole.

Even where potential job contacts were nominated by individuals who rely on AAC, only one link was found between job searchers who rely on AAC and the employers they nominated. The lack of connections or linkages is consistent with what we would expect where a structural hole divides employers from a group of prospective employees.

If there is a structural hole separating potential employees who rely on AAC as a group from employers other than those whose business involves serving the AAC community, then where might network bridges be built to effectively span this structural hole? To be effective such a bridge should be short, linking employers and AAC users in just one or two steps. It should also link many employers and many AAC users, and be able to serve as a trustworthy reference to employers. We found that the nodes that were most effective in linking AAC users with employers were (1) a university with strong contacts with the AAC community and (2) a disability employment organization with strong contact with potential employers.

If we are to bridge this structural hole, effective bridges must be built among organizations who are linked to the AAC community and those who have strong connections with potential employers. Offices of Vocational Rehabilitation might work to provide such bridges. So might Centers for Independent Living and universities with strong programs in AAC.   Identifying effective strategies for bridging the structural hole among potential employees who rely on AAC and potential employers offers a new direction for research, policy and practice.

In summary, during the past five years, research conducted at the Institute on Disabilities at Temple University offer the following lessons learned:

- *Human capital* – skills, including information and communication technology skills are needed for employment.
- *Human capital* skills can be improved through effective training, such as provided by ACETS, but it must begin earlier, during the school years.
- *Human capital*, while important, is NOT enough.
- *Social Capital,* including job-related social networks, are also critical.
- Job-related *social networks* among people who rely on AAC are smaller in size and more redundant, especially for those who are unemployed and should be expanded.
- Both specialized and generic *communication and information technologies* can play important roles in developing and sustaining job-related social networks.
- There is a *structural hole* between job seekers who rely on AAC and potential employers.

- Finally, there are promising strategies for reducing or bridging this structural hole so that potential employers can know skilled and qualified job seekers who rely on AAC.

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Interactions While Starting a Business

Scott Palm, B.S.
Seattle, Washington

I have a dream as well. So Let me start by telling you about my dream. My dream involves my own business. I'm starting a business called Palmtree Enterprises.   you might be wondering What kind of business Palmtree Enterprises is. Well besides the obvious fact that I'm Scott Palm, Palmtree Enterprises provides a vision of what's possible to communication device users, speech-language pathologists, families, friends, or any others through informative demonstrations.

   The reason I want to start Palmtree Enterprises is to help others because I know AAC has opened many doors that would be closed otherwise. I used to feel stupid, shamed, weak and worthless because I couldn't express myself . In the eightys, I was working for a u,s, congressman. One time, the national u cp telathon was happening and the congressman thought since it was a election year he should appear on the local portion of the telathon with me. I went down to the tv studio and met him. This was before dectalk speech came out so my communication device wasn't clear enough to be understood in person, not mentioning to be understood on tv, like it would be understood today.   so when we did the spot, I only could say one word. that was a yes. Some of you know me. When have you known me to say just one word? A better question would be. Can anybody say just one word? Least to say, I felt shamed because I was an adult with thoughts and feelings like anybody else, and I had reduced myself down to one word.   Have you felt like this before?

   I couldn't express my thoughts. The limits of technology always are with us. We all know we can do things that we couldn't do five years ago. Expressing ourselves clearly twenty-five years ago was but a dream, and today it's a reality. Some people express ourselves better than others. We all have thoughts, ideas or feelings to get out, and it would be a crime to do nothing. We need to pass on our legacy to the next generation, because I don't want them to go through the same shameful experience I had.

   But now using Unity, those doors aren't just opening now rather they're being pulled off their latches. It has empowered me. There isn't one person on this earth I can't communicate with. Well maybe not Spanish, German, or Japanese, but when it comes to English I have it covered.   For example, for star trek fans out there, I have talked to this woman. And I talked to her twice few years apart at two separated star trek conventions.   And for those who don't know, this is Nina Visitor who played Major Kira on Star Trek: Deep Space 9. I had about sixty seconds with her. With Unity, I told her I was a fan and asked her a question. I learned in those sixty seconds that I had strength and self importantness. Although it was her job to listen to me, I had strength to speak up. And I came out of my shell and engaged somebody in a spontaneous conversation. Thus,I feel important.

Communication at work

   And now I want to pass that on to the next generation of people who use a AAC device. They should have an opportunity to reach their full potential. All due to respect, a speech-language pathologist can't motivate somebody to use their device the way another user can. As the device users in this room know, there are difficulties we go through that a speech-language pathologist is powerless to help with. One such difficulty is to motivate a user. Some times a speech-language pathologist can try everything and anything, and nothing works until that person sees somebody else using a device. Then it clicks in his or her mind that they can do it too. ['] And. That's where Palmtree Enterprises comes in.. And now, I would like to move on and talk about the genesis of my dream. When did this start you may ask? Let me tell you my story.

Well, it all began in the fall of 1992. I just had gotten my Liberator that previous April. And if I remember correctly, Barry Romich just had written a macro to give a speech. I didn't know it at that time, that macro eventfully has created a career for me. I was working for Edmonds city public works doing data entry. It was a new experience for the city. My job developer came up with the idea of me giving a speech to the city counsel about my job. I was scared to death. I just had put the speech giving macro into my Liberator but I didn't know if it would work when I needed it. But my job developer and I wrote a speech about my job in a notebook in my Liberator.

   Then the night of the speech came. My scared feeling was replaced with a blend of emotions. I was excited and nervous. I was excited because I knew I could do it. But I was nervous about how it will turn out. I invited my speech-language pathologist to be there, and she was in the audience. After some technical issues with the mike, I did the speech, but something started to happen. I began to have the feeling that I was in charge of the entire room. Everybody was listening to me. It was really intoxicating. I never had a full room of people listening to me before. The speech was a huge success. Later, I had termed it as the Liberator effect. From that seemingly unintended event, I did more and more speeches.

   I began to speak on subjects from my life experiences in a nursing home to a chronical and historical account of the communication devices I had used over the years. They filled me with a sense I can try anything. Okay maybe not nude sky diving, and I'm not considering it. Talk about blocking out the son. But I have gone to a bar, and entered a karaokee contest. By the way, I won $25. Thank you Snoopi. Then PRC started the ambassador program. This was when I reeeally, excelled. My speech-language pathologist recommended me to Analee Anderson, the regional representative for Washington state at that time. I was eager but I didn't know if I was that good. But when I met Analee, she assured me that I would do fine.

   My first assignment was to help man the PRC booth at the alsha conference in Seattle. I felt proud, because as some of us know prc doesn't make just anybody an ambassador, only the best. I did well at the PRC booth because I had four or five people surrounded me all the time. My second assignment was the CAMA tour in Missoula Montana. While I was there, I met a four year old girl who just had gotten her Liberator. The Liberator was almost as big as she was. She was incredible. She knew signing, and I knew some signing and that was how we talked as well as our Liberators. She was almost as fast as I was. That was the seed of Palmtree Enterprises because if she could do it, anybody can.

   When Analee got a promotion, Mia Emerson took over for her. I continued to man the PRC booth at conferences. And then, Mia started me to help her with device classes. Something started happening. People started to say that I was reeeally good at what I was

doing. Some professionals thought I could do this as work, and that I would be successful at it. That made me to think maybe I can do this as work. This also was the moment that I knew this was what I was suppose to do with my life. I have done many other things as possible careers, but helping other people with their devices always has cropped up on the way. And every time it has, I had helped somebody to be a better communicator. When I do, my spirit soars. It was becoming crystal clear that this has a real chance to Mia and other speech-language pathologists.

In December of 2004, I joined an agency called Washington initiative for Supported Employment, who helps people with disabilities to start their own businesses, through a team approach. And I have to say that my time with WISE has been a quite learning experience indeed. The beginning step to start that business was that I had to take self employment training. I found it reeeally, stimulating, because I saw the other sucess stories of people who had their own business. It reeeally, refueled my enthusiasm to do it myself. Then I needed a team who would know the AAC community, as well as Division of Vocational Rehabilitation, Snohomish County Division of Developmental Disabilities which is the county I live in, Service Alternatives which is my residential service provider and others. It was rather like putting a puzzle together. I had this mental picture in my head of what the team should be. And now, I needed to find all the pieces, or people, to make my team a reality.

First, I contacted Mia Emerson, because she had worked with me for years when I work as an ambassador. I thought having somebody from the company that makes my communication device would prove valuable. From there, I drew upon my contacts in various other areas of my life. I had two team meetings. At the first meeting, I only had four people there. It was clear I was going to need more team members to make Palmtree Enterprises a reality.

A possible resource of getting team members was that I'm on the Snohomish County Developmental Disabilities Advisory Board. The people on the board are from different backgrounds, so I felt that I needed some people who are on the board. So I told a number of my fellow members about my dream for my business, and then I asked Stuart and Susan from the Division to be on my team. Then I assigned each member an objective. Susan and Stuart's objective is to keep the rest of us from going off on some wild direction. From there, I felt I needed a strong presence from the AAC community. I selected Mia Emerson and my old speech-language pathologist, Kathy Smith. I have known Mia for about five years, and I have known Kathy for twenty-five years. Between them, I have about thirty years of experience. So to make a long story short, I had a second team meeting, and I had about fifteen people.

I had Anne Mac Murray, a representative from Service Alternatives which is my residential provider. I had Andrea Diamond, a representative from the Washington assistive technology foundation for possible new computer.   I had Barry alber le, my Division of Vocational Rehabilitation counselor for the vocational aspects. And I had Natlie, a representative from the disabled resource connection, and she is a social security benefit planner.   But the most essential part of that meeting and all through my work with WISE was my personal agent, Sally. Yes, ladies and gentlemen, that's reeeally, my personal agent. With out her, none of this would happen.   The result of the meeting is as follows. As standard procedure, dvr wants to do, and is doing a feasibility study on Palmtree Enterprises. They think it's feasible,but they feel that transportation will be a big barrier. They have directed me to check into transportation options, so I'm checking into my own van and

driver. Meanwhile, Palmtree Enterprises had its first client earlier this spring. The speech-language pathologist from the Mukilteo school district saw me at a PRC device class. She had a young Pathfinder user who wouldn't use his Pathfinder spontaneously. Well after a month of four sessions of one hour each, I was told that he went into his classroom, and used his Pathfinder to ask how everybody was. Everybody was stunned, because he never had done that before.

   To conclude, I would like to re state three essential things. The first one is that it took me seeing other people doing this self employment stuff to further energize myself to do it as well. The second thing is that with out people like Stuart and Susan from Snohomish County Division of Developmental Disabilities, Kathy my former speech-language pathologist, Mia from PRC, Sally from Washington Initiative for Supported Employment, and others, this wouldn't be possible. And third, this is the most exciting time of my life. As I said before, a speech-language pathologist can't motivate somebody to use their device the way another user can. I have been called in to help on several occasions. Finally, I have a chance to make a difference, because I have something to give. And my team is helping me to do it. Thank you.

Out and About: Using a Communication Aid at a 7-11,

at an Emergency Room, and on a Date

Bac Shelton, B.A.

My name is Bac Shelton from Ocean Springs, Mississippi. I live in Starkville, home of the Mississippi State University. I was born in Vietnam in 1970 and came to this country when I was 2 or 4 years old. I could not walk or do anything on my own. I received physical therapy at Keesler Air Force Base in Biloxi and learned how to walk. I went from one Special Ed class to another until one special teacher recognized my abilities and fought to have me placed in a regular 1st grade classroom. I was 8 years old. I received the same amount of homework and took the same tests as all the other kids. The teachers gave me some more time on a test if I did not finish it on time. Throughout my childhood the other kids made fun of me calling me all kind of names. I fought only twice for those particular problems. My family moved from Biloxi to Ocean Springs in 1982. I made more friends in the Ocean Springs schools than in Biloxi, but I came across the same problems where kids made fun of me. I learned to ignore them this time.

From the first grade through graduating high school I had to write everything down when I wanted to speak. Believe me, it wasn't easy, but after a while I had gotten used to it. After high school, I took a year off to decide what I wanted to do with my life. A former counselor and friend told me about this small computerized device, the Touch Talker, which could help me communicate with everyone. Since my father was in the Air Force at that time, the Air Force purchased my first communication device. I had to learn what these buttons were and where to find them on the keyboard, on my own.

During the Mississippi State University years, the WILD and CRAZY YEARS for me, I switched to a smaller and lighter device called the Delta Talker, which I'm using now. It took me about 6 years, but in the fall of 2000 I graduated from MSU with a Bachelor Degree in Fine Art.

For the last four or five years now, I have had the pleasure to do some volunteer work for the Cerebral Palsy Foundation of Mississippi. I designed a T-shirt for a foundation special event in 2003. In October of 2003, the UNCPF of Mississippi board members made me their vice president of the foundation. I have been working as a consultant, with the Prentke Romich Company that makes these devices, for the last three or four years now. I am getting paid just like one of their professional PRC regional consultants. I usually go to various places like schools and special events in Mississippi to talk to people about my experiences using a communication device. In August of 2003, I received the Pathfinder by the company in which they helped me get it from Medicaid. In October, November, December of 2003; 2004 of March and July, and 2005 of January, I had the pleasure to travel to Alabama, Arkansas, Florida, Oklahoma, Maryland, Tennessee and Texas to share my experiences.

As I mentioned about Florida of this year, I met a drop dead beautiful young woman named Faye Warren. She has cerebral palsy and uses a Pathfinder, too. She is an ambassador and a consultant for the company in Florida. We have been seeing and calling each other ever since the conference. When I went down there for my birthday, she had no idea that I was coming, but her family did. Ha Ha Ha. When she saw me, her face just went like this for 10 minutes.

She said that she thought she was dreaming. She also said that she will get me back some day. I told her that I was really, really scared of her.

Because I received some graduate teaching courses from Jackson State University for two and half years, I have a research job at the TK Martin Center for Technology and Disability on the Mississippi State University campus in 2004. The TK Martin Center is a place where disabled people can get an evaluation by their vocational rehabilitation counselors or someone from the school districts to get something to enhance their livelihood. I teach an art program for the children with or without disabilities. TK Martin Center has a camp for the children who use a communication device. We have been doing this about seven or eight years now. Each year, we do something different like last year we did a camp on Hollywood and TV. This year, we did a Survivor show. Last October, the TK Martin Center got another grant from the federal government to allow my art project to continue for the next three years. Don't you feel so sorry for the people at the TK Martin Center from having to put up with me for the next two more years? I don't. Ha ha ha.

Thank you for allowing me to share my experiences with you and just remember the importance of believing in yourself and always doing your very best.

Jobs and Medical Community Relations

Faye Warren

As a proud Floridian, who attended and graduated from Orange County Public School System, and recently earned a BFA from St. Andrews Presbyterian College, I care about student performance and our next generation who will contribute to the our state's economy base. In the era of "No Child Left Behind," schools are working hard to assure that ALL students' academic and personal development performance levels are progressing. But how is that achieved for students with disabilities or special health care needs? Are professional development opportunities in your area meeting these needs too? Do exceptional education students see people with similar needs making it in this world?

As a person who is disabled and has been a successful student both at the secondary and post secondary levels, I am an asset to programs and projects seeking a qualified consultant, mentor to those who have speech impairments, public speaker, an independent contractor, and inclusion facilitator. As a mentor, I will teach your teenagers independent skills, social skills, communication skills, language skills, self-determination skills, self-esteem skills, self-motivation, computer skills, if needed, and problem solving skills. Through the use of on-line technology (emails and list serves) my skills and abilities lend themselves to assist in educator in-service programs and on a classroom basis in skill areas such as: improving students' communication, language, socialization, survival and adaptation, developing mentoring programs and how to manage health and related needs that will maximize attendance and education performance. As you review the enclosed vitae you will note that my varied experiences make my talents and expertise truly "reality based." I offer my skills and talents as a consultant and a mentor to an individual with disabilities or someone who works with people facing these challenges to help fight these battles. I would welcome the opportunity to discuss via email potential services I can provide for people with disabilities, their families and/or their service providers. My consultant services are on a one-on-one basis or in a team approach. It is my professional goal to assist others with physical challenges to become successful community participants who live fulfilling lives in the world. I also coach the parents in how to teach the children to become more sociable and more independent As a public speaker, I discuss with audience how my communication devices, my Touch Talker, Liberator and Pathfinder have impacted my life and make a difference in my life. Furthermore, I talked how I overcame my hardships throughout my life and accomplished the impossible such as going to my neighborhood high school without any assistance and then graduating from an away college. As an Independent Contractor, I create communication boards for special education teachers and other professional to communicate with their students. My Jobs are quite challenging, but I love what I do. That is to help people to communicate and succeed in the world.

Community Connection: The Role of Employment in Reducing Loneliness

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Introduction

Older adults with cerebral palsy, including those who use AAC, experience a greater degree

of loneliness than older adults without disability (Balandin, Berg, & Waller, in press).

However, there is little information to date on the underlying causes of their loneliness or the

factors that mitigate against feeling lonely. In this paper, work, retirement, and voluntary

work are discussed in light of the role they play in contributing to or mitigating against the

experience of loneliness and engendering community participation.

Method

Participants

Seven adults with cerebral palsy, four men and three women, participated in this

study. The participants had previously taken part in a measurement of loneliness study

(Balandin et al., in press; Berg & Balandin, 2004) and had expressed interest in being

involved in a larger qualitative study that focused on loneliness and cerebral palsy (Ballin,

2004). Information about the participants is provided in Table 1.

Table 1: *Summary of the Background Information of the Participants*

Participant No.	Gender	Age	Communication System	Employment Status	Hours of daily assistance
1	F	55-59	Natural Speech	Full Time	<1
2	F	55-59	Natural Speech	Part time CAS	>6
3	M	60-64	Natural Speech	Retired, voluntary work	<1
4	F	60-64	Natural Speech	Unemployed	<1
5	M	45-49	Speech Generation Device	Unemployed	>6

| 6 | M | 55-59 | Speech Generation Device | Retired, voluntary work | >6 |
| 7 | M | 40-44 | Speech Generation Device | Part time CAS | 4-5 |

Four participants were considered to have a severe physical disability, as they required more than four hours of daily assistance. Three participants were considered to have a mild physical disability, requiring less than one hour of daily assistance.

In-depth Interviews

Prior to the commencement of the present study, a total of 6 themes and 42 topics that were relevant when considering loneliness were identified by adults with cerebral palsy and a group of researchers experienced in ageing and disability in two focus group discussions (Ballin, 2004; Ballin & Balandin, 2004). The first author had used a thematic analysis (Luborsky, 1994) to identify these themes and topics from the transcripts of the two focus groups (Ballin, 2004; Ballin & Balandin, 2004).

Interview Procedure

The first author conducted the in-depth interviews. Participants were interviewed twice at a convenient time in their own home. Each interview lasted between one and two hours and breaks occurred if participants requested them. The interviewer asked each participant if she could record the interviews on audiotape, so that she could transcribe and analyse it later. Participants were assured that their recordings would be kept confidential and that they could listen to the recording of their interviews and remove information or wipe the tapes if they did not want the material to be used.

Participants discussed how they felt each theme and the topics identified previously

contributed to or mitigated against feelings of loneliness. Probes were also used to elicit

more information (Liamputtong Rice & Ezzy, 1999). The order of presentation of themes, the

exact wording of questions, and the probes for greater detail were unique to each interview

(Kaufman, 1994), as each participants' experience of loneliness was unique.

In keeping with the guidelines for thematic analysis (Luborsky, 1994), the interviewer

reflected back to the participant the main themes and topics of the interview (e.g., "While we

were talking it seemed that people's attitudes came up a lot. Is this idea an important topic

for you?"). Luborsky (1994) suggested that the exploration of themes with a participant is

important because there is no absolute criteria for themes. Asking for direct feedback meant

that the interviewer was able to check that she had understood the main responses correctly.

Verification of the interpretation. The interviewer met with each participant a second

time. In the second interview, she summarised what the participant had said about each topic

and asked if the participant wanted to add any further comments. This enabled verification of

the participant's responses and a further understanding of each participant's experience of

loneliness (Creswell, 1998).

Results and Discussion

Work and work training

The 3 participants who were working or had previously worked believed that

workforce participation reduced vulnerability to loneliness. Participant 3 stated, *Work is a big*

part of my life. I go to work. I'm not lonely. I've got a lot to do. How can you be lonely if you

are employed? Participant 7 referred to his Community Access Service (CAS) as his place of

work. He considered accessing this non-vocational service reduced loneliness, *because my friends are here*.

Participation in the workforce contributes positively to psychological well-being and provides adults with a sense of identification and opportunities for social contact (Freedman & Fesko, 1996; Parent, Kregel, Metzler, & Twardzik, 1992). These results indicate that this is also true for adults with cerebral palsy. However, most adults with cerebral palsy experience limited opportunity to partake in full-time employment (Balandin & Morgan, 1997, 2001). Balandin and Morgan (2001) surveyed 78 adults with cerebral palsy in Australia, who use AAC. They revealed that only 22% of survey respondents had full- or part-time employment. The participants in this study highlighted some of the barriers to participation in the workforce.

Barriers to workforce participation. A total of 4 participants discussed the difficulties in accessing the education to acquire work skills. They considered that not having access to work contributed to loneliness. Participant 2 noted,

> *I haven't had a job. I did look at it but I've got no skills. And to do it, a lot of support systems would need to be put in place. For a person like myself I would need a person there with me for mealtime assistance and toileting, perhaps four hours a day or six hours.*

Two participants considered the difficulties in forming relationships with work colleagues contributed to feelings of loneliness. Participant 3 remarked,

> *They always invite one another over, I always get left out. It's like it's over. They go home and I am left on my own and I don't think they are aware of what they do. I gotta tell you that that makes me feel very lonely.*

Relationships with colleagues play an important role in the degree of social connection experienced at work. Non-inclusive attitudes in the community towards people with cerebral palsy will have an impact on the development of social networks.

One participant mentioned the difficulties in communicating with colleagues at work. He stated,

> *Timing is my biggest enemy. Some people don't take the time to listen. At work, I know I have got a small space of time. How do I get what I want in that space of time, to say what I've got to say? I've got a mind. I've really got a lot to say, but only that much time to say it. And that's a problem in meetings too.*

Insufficient time for communication at work will limit the opportunity adults with cerebral palsy have to engage in meaningful communication. This may result in difficulties forming meaningful relationships and feelings of loneliness.

These results signal the importance of ensuring older adults with cerebral palsy are provided with opportunities to participate in employment. This includes: (a) ensuring that adults with cerebral palsy are provided with access to work training, (b) ensuring that work peers without disability receive appropriate training for interacting with colleagues with a disability, and (c) ensuring that the communication partners of adults with cerebral palsy are provided with support and education in communication strategies, so that these adults are able to participate in meaningful communication.

Retirement

Two participants had retired from paid work. However, Participant 6 stated, *I was forced to retire*. He considered his forced retirement contributed to loneliness. He added, *I miss work. I miss being busy.*

Forced retirement can reduce an adult's sense of personal control (Peplau, Bickson, Rook, & Goodchilds, 1982). Indeed, researchers have commented on satisfaction with degree of autonomy as an important factor in mitigating against loneliness (Tijhuis, de Jong-Gierveld, Feskens, & Kromhout, 1999). Therefore, adults who are able to plan for their retirement are likely to feel satisfied with their degree of autonomy. It is likely that they will experience less loneliness than older adults who are not provided with the opportunity to make decisions about their retirement.

Retirement may also result in changes to financial resources. A total of three participants had superannuation or retirement schemes. These participants claimed the income superannuation provided for retirement reduced susceptibly to loneliness. Participant 3 said,

> *I get a superannuation pension. I was able to plan that. I've been able to pay my house off. For many people with disabilities, superannuation is not available. Without that life is very hard. It has made me a lot more independent.*

The participants agreed that many adults with a disability do not have superannuation schemes. Participant 3 added,

> *For a lot of other people, it's a very big issue. Most people with a disability are not able to build up their nest for their retirement and they don't have any options at all.*

Superannuation is important because it provides economic security following retirement. Therefore, older adults with cerebral palsy, who have planned for retirement, will be able to maintain the lifestyle they had previously enjoyed while earning an income and enjoy a good quality of life as they age. Indeed, these three participants considered having a superannuation scheme reduced their susceptibility to loneliness. However, many older adults with cerebral palsy have limited opportunity for paid employment and previous

research has indicated that many of these older adults do not have such schemes (Balandin & Morgan, 1997). Indeed, four participants did not comment on having a superannuation or retirement scheme. This result supports Balandin and Morgan's (1997) proposal that these older adults may require adequate financial information and support.

Therefore, these findings emphasise the need to improve the support and education about income older adults with cerebral palsy receive. This support includes (a) ensuring older adults with cerebral palsy have the opportunity to participate in paid employment, in order to facilitate their ability to afford social activity and to have a superannuation scheme and (b) providing education and support in financial planning.

Voluntary work

Two participants participated in voluntary work. They were positive about the impact of volunteering in reducing susceptibility to loneliness. Participant 3 commented, *Community involvement is a big part of my life. I'm very active*. However, 2 participants wanted to volunteer and had experienced difficulty accessing voluntary work. They considered this contributed to loneliness. Participant 2 stated, *I tried to be a volunteer, but the organisation didn't want me*.

The finding of the importance of involvement in voluntary work in reducing feelings of loneliness supports previous research (Musick & Wilson, 2003; Warburton, Terry, Rosenman, & Shapiro, 2001). Warburton et al. (2001) noted that voluntary work provided opportunities for social interaction, the chance to maintain involvement in the community post-retirement, and the ability to engage in productive activity. Participants 3 and 6, who had previously participated in full-time employment, considered voluntary work offered

them a meaningful role in the community and enabled them to maintain their engagement in society.

Therefore, considering the effects of participating in voluntary work in reducing susceptibility to loneliness in older adults with cerebral palsy, it is important older adults with cerebral palsy are provided with opportunities to partake in this activity. However, in Australia, not many older adults with lifelong disability engage in volunteering. It is clear that further research is warranted to investigate the barriers to volunteering for adults with lifelong disability in light of the association between volunteering and enhanced life satisfaction and well-being (Warburton et al., 2001).

Conclusions

The results of this study indicate that workforce participation, retirement, and volunteering are important topics to consider in the discussion of loneliness in older adults with cerebral palsy. These topics were discussed in light of the impact they have in contributing to or mitigating against loneliness. Older adults with cerebral palsy are valued members of the community. They may require support to access employment, superannuation or retirement schemes, and voluntary work, so that they may enjoy a good quality of life as they age.

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Community Interactions: AAC and Being a Church Member

Dennis Hollman

I,ve been a born again Christian on and off since 1996, and steadily since 2001. Within these last four years, I,ve seen and experienced many wonderful things. I,ve also joined a congregation that has grown accustomed to interacting with an AAC user in myself, and it was the greatest thing I could possibly have done.

I am not representing myself at PEC this year. I,m representing Jesus Christ, and my church on Long Island. The Holy Spirit has instructed me to be bold and speak on what it is like to be a born-again Christian that uses an augmentative communication device.

Two years ago, when my friend brought me to my present church for the first time, I was introduced to a concept called the "G12 vision", developed by Cesar Castellanos from Bogota, Colombia. In a nutshell, this vision is designed to develop groups of twelve to witness about Jesus in hopes of finding new believers. When each of the original twelve disciples went out and found twelve more people who believed in Jesus (or didn,t know Him yet), there was twelve groups of twelve that were

witnessing as well as the original group of twelve. Each group of twelve is collectively known as a Œcell, group. A cell group meets once a week; mainly to talk, pray, and encourage one another.

I,ve been in a cell group close to a year and a half. As being the only AAC user in the congregation, there was an adjustment period on all sides. I had to adjust to my group, and my group had to adjust to my Pathfinder and me. This adjustment period was very short. They immediately accepted me. Ever since then, I,ve constantly been encouraged to go out and tell people about Jesus and how He has worked in my life.

The Four Stages to Discipleship

To disciple people is not an easy task for a non-AAC user. It,s not easy for them to tell others about the Word of God. The key is whether the person accepts or rejects what he/she is being told. Imagine how much harder it would be for AAC users; we have extra work to do. Before I can start ministering, I need to explain to them about my Pathfinder. I have had instances where somebody would ask me a question then walk away as I was typing. They would think I had a video game on my lap instead of my voice.

There are four stages to disciple a new believer: win, consolidate, disciple, and send.

WIN

New believers are brought into the church through evangelism, Sunday celebrations or "net meetings". (Net meetings consist of all the same-sex cell groups. It,s better for men to evangelize to men, and women to evangelize to women). Once this happens, the group of new believers is taken to a separate room and there is where the consolidation begins.

I remember how I started on my walk with the Lord. I went to church before this, but I wasn,t putting my whole self into it. I was with a non-AAC user friend of mine that I,ve known since sixth grade. He brought me to his cell group at his pastor,s house on a Tuesday night. I was a little nervous because these men never met an AAC user, much less know what AAC meant. We adjusted to each other fairly quickly. I knew that,s where I wanted to be. Whenever I want to talk, I,d program what I want to say. Then I,d raise my hand. They made me feel like there was nothing to worry about, and they showed me that they understood My Pathfinder AND Me. They even tell me to use it to spread the Word of God.

CONSOLIDATION

In my opinion, this is where the fun (and the work) really begins. When a new believer enters our church via cell group or a Sunday service, they are asked to fill out a contact form so either a cell leader or one of our pastors or a church elder can contact them to minister to them (ideally within 24-48 hours). In my case, two people ministered to me almost every night; one of them was my friend, and the other person I met through the church. To this day, I still get calls from people from the church, asking me how I am or telling me they read a scripture that reminded them of me.

The process continues through a special three-day weekend known as an "encounter" weekend. These encounters focus on one,s relationship with the Holy Spirit, and essentially we have a one-on-one encounter with Jesus. Throughout the weekend, we learn the meaning of the cross and encounter different demons that we may have.

Before an encounter, new believers are required to take a three-week class (on Sunday morning before service) called a pre-encounter class. This class is designed to prepare the new believer for the very powerful weekend.

About a week before an encounter, the new believer gets a call from a member of the church that has completed the G12 program. That person is called a Œguide,. The guide has a responsibility to whoever has been assigned to him/her, in case they need help before or during an encounter.

I received a telephone call from one of the elders of the church, Roland, who happens to be a good friend of mine. He,s also in my cell group. Roland,s job was simply to be available to me.

I,ve been on two encounters so far. However, there are three things from my first two encounters that have stuck with me. 1. I can hardly fathom the fact that I was put here, in my condition, to spread the word of God. 2. AAC is a gift from God. 3. Even though our voices don,t work too well, God can understand us perfectly, but he gave us AAC not only so we can be heard and understood by others. That,s why he put PRC here and that,s why he put Semantic Compaction here; to enable us to speak and to spread the Word.

Discipleship

The goal of every new believer is to lead his/her own cell group. When each disciple finishes consolidation, they go to the next level, which is the "school of leaders". In the school of leaders (which meets weekly for nine months), the disciple is trained to become a cell group leader. This level is divided into three sub-levels; School of leaders One, Two and Three.

Each of the new cells continues to receive help, advice, and support from his/her original cell groups. At this point, we no longer have just one group of twelve witnessing about God,s Word, we have TWELVE groups of twelve.

Then I had an idea. What if an AAC user had the opportunity to tell some unfortunate person that Jesus, the Savior loves him or her? I was in that position. I know a woman that is really down on her luck. She,s not an active Christian. Even though men shouldn,t evangelize to women, I felt I had to talk to her. All I tried to convince her of was that Jesus would not give his children anything we can,t handle. I couldn,t say anything else. It,s not up to us to save souls, but it IS our job as Christians to lead people to the Lord. In my case, He,s using an AAC user to witness and disciple.

SEND

When each person of the original cell has their own cell of twelve, the last step of the process is to form teams to help out at the next encounter, as well as develop the next School of Leaders. More and more teachers are needed as the multiplication continues. Then the whole process starts over again, starting with the pre-encounter. This is known as the Œprinciple of multiplication,.

Conclusion

When I decided to write this paper, I was still in the Post Encounter class, but I saw this conference as an opportunity to share what I know and what I believe to be the truth. My cell group always tells me that Jesus is going to use me. I always wondered how and when.

I was watching my favorite television evangelist, Joel Osteen in the middle of June, on a Sunday night. As I was listening to his sermon, I came up with my topic for my paper. The Lord told me to speak to other AAC users about the Word of God.

I,m reminded of a passage in the Bible that is similar to what AAC has done in our lives. In John chapter nine, Jesus encountered a blind man.

To make a long story short, Jesus rubbed mud on the blind man,s eyes and made him see.

A similar thing occurred to AAC users. Through Bruce Baker and Barry Romich, Jesus rubbed mud on our mouths to enable us to talk, even though our voices are electronic. AAC is a gift, and we should use that gift to spread the Word of God and help others see that without Jesus and AAC, none of us could be heard.

Leadership-Charting a Course

Clare Bonnell, ISAAC, Executive Director

[a half sheet of paper placed on each of the table with the questions we are seeking answers to (brief, simple, 16 or20 point) with my and Vic's contact info.

Introducing myself:
Hello everyone I am pleased to have this chance to speak with you. My name is Clare Bonnell and I am from Toronto, Canada. I have no business standing up here! I am not an AAC user, I have no disabilities that you can see, or that I will confess to!, I am not a therapist, clinician, teacher, researcher, technician, manufacturer or family member of someone who uses AAC. I am here because I am the Executive Director of the International Society for AAC (ISAAC) and have a habit of wanting to develop the potential of anything I get involved in. Maybe also because I know a little about leading.

I will be asking a few questions that can be answered with "yes" in this half hour. Please be ready to answer "yes" if you want to answer yes. On each table is a sheet of paper with the more important questions I have for you and some contact numbers in case you want to answer later or say something you can't say in public! OK here's the first one…………

Who had heard of ISAAC before this meeting?

Why I am here:
I am here to tell you about an adventure ISAAC is starting on and to invite your participation.

First a little about ISAAC for the people here who don't know it very well- very short and not boring.
 (*use brief power point on ISAAC here*).
I understand we have people from the US, from Canada, from the UK from Latin America ? and Australia. Any way you like let's give a shout for international cooperation.

Leadership in ISAAC:
"The ISAAC board of directors decided in 1998 that there would always be at least one person who uses AAC on the ISAAC Executive Committee.

  The role was created to ensure that all of ISAAC's activities include the perspectives of the members who use AAC. This keeps ISAAC focused on it's reason for being: providing the best possible communication for people with complex communication needs anywhere in the world. Who is in a better position to know if this is being achieved than those who rely on AAC to communicate? Michael Williams[from California], was the first person in this leadership role and Anthony Robertson[from the UK], whom you may know from previous PEC meetings, was the second (*recognize Anthony's brother and Anthony's colleague*). Currently Vic Valentic [from Canada](*recognize Vic*) is in this role. In this volunteer position, Vic leads an international committee of ISAAC members who use AAC. Since 1998 all 14 chapters of ISAAC have established a similar position on their boards. Some of ISAAC's other international committees have added or now include people who use AAC. We are learning what this requires to truly be a matter of equal participation.

These positions are an unusual opportunity to lead because they are in an organization dedicated to AAC that has an impact on the entire field.

The first time most people join a Board, they have no previous experience of the feel of being in a decision making group or the behaviour, rules and expectations that go with the job. Learning these skills is even more challenging when you may be the only person in that group using AAC. ISAAC is no exception.

I am assuming some participants who use AAC here have experience in a leadership position. Am I correct? *Wait for two or three "yes" responses*
We'll pick this up again in a minute

ISAAC has a **vision of people who rely on AAC participating fully in leadership roles in many contexts**- a committee at work, in the community, on a non-profit board, in public office and so on. The leadership positions within ISAAC offer all of us a way to learn what tools are needed to fulfill that grand vision of leadership outside the AAC community.

But it is a long road from the concept to the reality. (*show the chart of stages of participation from token to leading*)

ISAAC wants to develop tools and provide leadership "apprenticeships" that will make equal participation of AAC users in leadership roles a reality. We want you to help us shape this adventure.(*maybe a picture of Luke Skywalker)*

First a quick overview of the ingredients of leadership in general…………
The Personal Qualities

Leaders have to want to lead, to make a difference. Leaders want to take risks. Leaders want to be committed. Leaders have to be willing to learn, make mistakes, to work hard. Leaders have to do their homework, to listen and work with people. Leaders get criticized to their faces and behind their backs. Leaders have to take a position on things (*read out the amusing comment about learning to be a leader in 60 minutes*).

The Resources you have

Time
Information about the tasks to be accomplished
People's abilities and skills
Maybe sometimes a little money

And in an AAC context……..
A supportive environment
The physical space where meetings are held has to be accessible. Toilets, beds, showers, food, transportation must work as smoothly for you as for the able bodied people on your board or committee. Everyone on the committee must play a role in ensuring this happens.

The psychological space (the head space of everyone on the board or committee) has to be committed to equal participation and understand what it requires of them.

Your input

Now I'd like you to talk back to me. Especially those of you who said yes you have had experience of being in a leadership role.

ISAAC is hoping some of you here will be interested in being involved in this pioneer work.

We need a place to start if we are to develop tools and guided experiences.

Identifying barriers is a starting point. Give me a "yes" if the following challenges are ones you have met or expect to meet in a committee or leadership role?

Communicating
- speed of communication in group discussions

- knowing how to interrupt or initiate comments and topics during a meeting

- understanding the language and processes involved in governance – such as making motions, approving a motion, amending a bylaw etc.

- knowing how to stay on topic, resolve issues, elicit information etc.

- having confidence to speak up at a meeting

- knowing how to contribute to meetings

People Have you ever or would you expect to encounter

- People on the committee you are on or leading who may not know how to talk with someone using AAC beyond tokenism and Yes / No questions at a meeting.

- Encounter people on your committee who may not know how to ensure the input of someone using AAC in situations where the meeting is electronic or virtual.

- Encounter people on your committee who may not acknowledge what the AAC user is contributing due to a perception that professionals know best.

- Encounter challenges in physically handling text and understanding text

Is there anything that I have left out?

These are just a start. ISAAC wants to work with anyone who is willing to give their time to develop tools to build leadership by people using AAC in ISAAC. Addressing these challenges is a start. And I haven't even touched on how to get that worldly experience that goes with leadership.

Thank you all so much for your attention. I hope some of you will have a few minutes for Vic and me to talk further with you during the conference. And of course we will bug you about JOINING your country's Chapter of ISAAC!

Randy Kitch-paper
Bruce Baker – paper

Stop the Nagging, Already!

Bruce R. Baker, *A.M.*

Some years ago, I invited an augmented communicator to a relatively small social event simply because I had a lot of respect for him, and I wanted to get to know him a bit better. He declined my offer with a letter of explanation. He said that being around me made him nervous, because he generally chose to use his natural voice and not his electronic communication aid. He felt embarrassed whenever his natural speech failed to be understood, everybody looking at him disapprovingly, then, turning their gaze to the person who designed his system – me! It was embarrassing, he said. I felt bad about this. First, because his perceptions were accurate, and second, because – although I thought we had failed him, not vice versa – people thought his non-use of the system would be offensive to me.

Later this afternoon, we are going to hear from Beth Anne Luciani. Beth Anne is going to talk to us about her use of communication aids. She's going to tell us how bugged she feels when people tell her she should use it more frequently and in situations where she feels a more efficient communication technique for her is not to use the electronic aid. She's going to tell us this with a certain degree of emotion. I talked about this with Beth Anne and suggested she take it as a compliment. The more talented and intelligent a communication aid user is perceived, that much more he or she will receive flack about not using the electronic communication aid.

I've been in this field now for 25 years and have met and talked to a large number of augmented communicators. As an electronic communication aid designer, I have seriously pondered non-use issues for more than two decades. I would like to share with you some of my conclusions. I'm sure many of you have already reached some of the same conclusions, nevertheless, …

1.   Stop the nagging, already! If the augmented communicator felt the use of his or her device was socially worth it at a given point, he or she would use it.
2.   Besides keeping our thoughts to ourselves, able-bodied types might better spend their time figuring out why the communication aid isn't working for that individual. As a manufacturer/designer, I do this all the time. It's enlightening.
3.   Howard Zipf, a classical philologist at Harvard in the 1940's wrote a series of important economic laws in communication, *e.g.,* words said frequently will over time become shorter.
4.   Zipf said that people will communicate in a way so as to conserve their energy – cognitive and physical – "Wad jeet f'lunch?" People are not "lazy," rather they are biologically driven to use the least energy to perform any given task.
5.   If a person does not use his or her communication aid, I look first to the cognitive and physical energy levels required to operate the machine successfully. In my opinion, this is one half the equation.
6.   The other half of the equation lies in the motives for communication and the emotions surrounding communicative acts. An excellent piece by a New York psychiatrist, Robert Seaver, M.D., appeared in the ASHA Special Interest

Division, Unit 12 Newsletter in 1997. In it, Seaver analyzes some psychological factors involved in communication:

    A. The sense of autonomy
    B. The social closeness of co-construction
    C. The validation of having one's natural speech understood
    D. The alienation and stigma caused by the electronic voice and the device itself

I would like to address each of these factors.

A.   Automony – When we're growing up, we do all sorts of things to show our parents, and particularly ourselves, that we are independent agents. Using a communication aid is often symbolic of a lack of autonomy to the user. Using a communication aid evokes stares and a sense of dependence.

B.   Social closeness of co-construction – I've been in many meetings when other voices override the electronic voice of the communication aid. I've been in many situations when the conversational partner ignores what is said on an electronic communication aid. It must be humiliating to the augmented communicator to be so frequently ignored, even when one is a superb AAC user.

        Many augmented communicators get to talk with relative infrequency. Having another person listen with deep attention to your words may make up for all the forced silence. Some say "It's a power trip" on the part of the AAC user, but I don't think so. I think it's personal closeness. Many AAC users experience deep isolation. They want the communication acts they are allowed to make be meaningful.

C.   Validation of one's natural speech – One of the most stigmatizing experiences of life is a speech disability. Speech disability ruptures all social conventions. People estimate other people's intelligence by their speech – *My Fair Lady* and Henry Higgins. People who stutter will remain silent, so as not to reveal their disability. To have one's dysarthric speech understood gives a boost to one's self esteem. It's like when an overweight person is asked, "Are you losing weight?" I can think of nothing more addictive for a person with stigmatizing speech than the validation of being understood by a friend or colleague.

D.   The alienation and stigma caused by the electronic voice and the "hardware" -- My mother became a consumer of assistive technology in her middle 80's. She began using a cane, which was okay by me, but when she started using a walker, I was unhappy. The walker symbolized her decline to me, and I was very pleased when she chose to go out with "just a cane." After a bad fall when she was 85, I believed she needed an electronic signaling device around her neck. Two volunteer, retired, electrical engineers from the local hospital delivered her base station and electronic necklace. They were so proud of their technology. "Let's not have the base station in the living room," I said. "Let's put it in Mother's bedroom." The base unit symbolized the power of technology to the engineers,

but my mother's decline to me. Also, I thought such a medical looking contraption in the living room was unsightly, *etc., etc*.

The similarity of my emotions to the emotions to augmentative communicators and their families only dawned on me a few days later. I got to see what I would be like as a consumer of assistive technology. I came to respect the technology only after it proved to be useful.

Well, those were some of my thoughts and conclusions and what follows is what wisdom I have been able to distill from my experiences.

I. Stop the nagging, already!
   Nagging is annoying and is only successful in fulfilling our own superiority—self esteem needs.

II. Explore lowering the cognitive and physical energy levels required to operate the machine.

I spent a lot of time and energy in my life trying to lower the cognitive and physical needs for AAC users. My solutions are embodied in my designs – to say anything further would be simply self serving. A brief summary will suffice.
   a. The system must be like a musical instrument – it needs to be played automatically – without thinking.
   b. User access must be physically non-laborious
   c. The user must feel that he or she is saying what he or she wants to say.
   d. Time frames can't be more than about ten seconds per word.

III. Provide some experiences which will show the usefulness of the technology

Seeing is believing. For some users, the Pittsburgh Employment Conference is enough. For others, personal success is required.

"Broken Speech" portrays powerfully the problems experienced by many people with communication impairments. It shows the situation of a person whose desire to play a broad role in life remains intact. It does not show but may give us some insight as to why people withdraw deeply into their own minds. "Broken Speech" is a work of art. It touches currents in the emotional lives of us all. It will make us laugh and think.

This year's theme for PEC@ is "Employment and Community Interaction." "Broken Speech" is about employment and community interaction. The authors have a negative view of electronic augmentative communication. You may agree; you may disagree. However,

almost everyone attending the Pittsburgh Employment Conference for Augmented Communicators will have an opinion. We will hear those opinions during the Town Meeting.

Broken Speech

Broken Speech is vulgar, sinisterly funny and at times painfully honest. The play explores the boundaries of a world based primarily on the spoken word. The viewer sees the world through the eyes of Tony, a person living with severe cerebral palsy. Physically confined to his wheelchair and not being able to formulate speech, Tony struggles to externalize his inner voice. The silence of Tony's world is abruptly shattered when Alex, an inexperience playwright is hired by the Speaking Differently organization to produce a play about Tony. In the process of creating the play, both characters develop a tender camaraderie. Within each other, both Tony and Alex find their own unique voices that connect them to each other.

"I am more than my AAC device": Individuals who use AAC
Discuss their Experiences in Community Leisure Activities

Gus Estrella, Laura-Jane Estrella, John Dattilo, Janice Light,
David McNaughton, and Meagan R. Seabury
The Pennsylvania State University

Leisure is an integral part of the lives of all individuals. According to Dattilo (2002) the concept of "leisure" integrates elements of activity, time, and the perception of freedom for individuals who choose to participate in meaningful, enjoyable and satisfying experiences. "Leisure" is not simply free time, some activity, or time away from work (Pavelka, 2000). Through leisure participation, individuals build important social relationships and increase their connection to others in their community (Devine & Lashua, 2002).

Leisure experiences are especially important to individuals with disabilities because they provide opportunities for participation that may not be available though traditional educational or employment activities. Through leisure participation, individuals with disabilities can express their talents, demonstrate their capabilities, and experience a variety of positive emotions (Dattilo, 2002).

Unfortunately, people with disabilities often experience physical and attitudinal barriers that prevent full participation in recreation and leisure activities. Bedini and Henderson (1994) interviewed 30 women with varying physical disabilities, and found that some individuals with motor disabilities chose not to participate in recreation activities because of negative experiences they had previously encountered. The individuals with disabilities also reported that their leisure experiences were often as handicapped by neglect, prejudicial attitudes, and discrimination as by anything that had to do with their physical disabilities.

Research Project

To date, there has been only limited research investigating the participation of adults using AAC in community recreation and leisure activities. To improve our understanding of important supports and barriers to participation in community recreation for individuals who use AAC, eight adults (four men, four women) with cerebral palsy who use AAC were invited to join an online focus group discussion on the topic of recreation and leisure. More specifically, participants were asked to discuss the following topics: (a) current participation and types of leisure involvement, (b) benefits of leisure involvement, (c) barriers encountered in the pursuit of leisure and recreation, and (d) strategies to overcome barriers and support participation in community recreation and leisure activities. The focus group moderators, Gus Estrella and Laura-Jane Estrella, posted questions, probed for additional information, and responded to participant postings. The discussion took place over an 8-week period, and the participants posted over 200 messages on community recreation and leisure.

The focus group discussion was still in progress at the time that these proceedings went to press. A full presentation of the findings will be provided at the conference, and will be available after the conference from:

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Getting Children Who Use AAC Ready for the "Real World", and Getting the "Real World" Ready for Them!

Robin Hurd

Abstract: Children who use AAC need to develop the following character traits to become successful adults: independence, persistence, a sense of humor, and the ability to form and express their own opinions. In this session, we will look at why these traits are so valuable in the lives of AAC users and we will demonstrate some new teaching materials being developed that encourage the development of these character traits while at the same time teaching children important science and language concepts.

Let's look at the character qualities needed for a child who uses AAC to become a successful adult:
1. independence
2. persistence
3. having their own opinions about life and the ability to express them
4. sense of humor

One of the keys to getting these character traits for our kids is to list them, and then to figure out the skills that are needed to build these traits.   I am defining *character traits* as *qualities* that have become ingrained in the person so much that they affect behavior without the person always being aware of it. *Skills* are defined as the *individual acts* that, when practiced regularly, add up to the character traits we have been talking about. For example, I become *independent* because I regularly *do things* to take care of my self.

So how are these traits developed? If the character trait to be developed is a sense of humor, then one of the skills children need to learn is "what is funny?" This sounds trite, but this is done by showing kids non-verbal signals that something funny has been said, or that the story being read is funny.   In my household, we also talk about how we ourselves interpret things as funny. In addition, when we see them doing something funny, or we witness an appropriately funny event, we make a big deal of it, because this is a skill we want to see developed. For example, whenever my family goes to the Aviary in Pittsburgh, my husband gets dropped on by a bird. We all talk about how Dad must have a target on his head, because the birds fly over and drop on him, but never anyone else. We actually imagine him with a target drawn on. However the last time we went, we discovered that Mom also has a target on her, it's just in a different place! Again, we all imagined Mom with a target on her for the birds to aim at. By doing this, we are developing a sense of humor in our children.

The skills that lead to persistence and independence are: increasing the number of things a child can do for himself (either with assistive technology or increased motor skills), making increased choices for himself, and having tasks or chores to do within the school or home setting.

We can break down all of the character traits we listed into skills that we can work to develop.   When we get to having an opinion and being able to express it,

something very interesting happens. The skills needed to develop this character trait are the same skills we call language development!   Let's look!

In order to have an opinion, our kids need to be able to get the facts, think about them, and come to a conclusion.   Getting the facts involves reading or listening, a language skill.   Thinking about the facts and coming to a conclusion both involve logic and reasoning, more language skills.

The final step in this character trait, being able to express opinions, involves putting together words that tell others what they have reasoned for themselves. Most definitely this is a language skill!

We can either look at building language skills as an end in itself, with the side effect of building an opinionated and expressive child, or we can look at language development as a means to the greater goal of helping our children to become opinionated and expressive.

I am choosing my words carefully here, because I want to subtly demonstrate that the character traits that will help our children become self sufficient adults are not necessarily looked upon as a good thing by the schools, and even sometimes by parents. So teaching the skills needed to achieve these traits may not be happening automatically within the school setting.

My husband David and I have been working on a series of books about the moon that are designed to meet the needs of not only children who use AAC, but children with other language and special needs as well. Part of our goal in writing the books as we have is to encourage children to observe the world around them and come to conclusions about what they see. This is not only what scientists do, it is also good practice in developing opinions and learning how to express them.

Along with the book itself, is a series of activities designed to supplement the child's ability to put together words to express the concepts learned, collect data, and practice creative writing.

The students' language learning is supported by the use of Minspeak® symbols within the book.   Combining symbols with words can help improve a child's reading comprehension, but visual supports can also help a child with language delays to better understand relationships between core words and grammar constructions that will help him to express himself more fully.

The Minspeak® set of symbols was chosen for its ability to differentiate the parts of speech easily by simply looking at the symbol similarities.   After reading the book out loud, the class will participate in sorting the symbols into groups based on what they have in common.   This is where the child with language delays can visually see how the various words are related to each other, and how the order of the words can determine whether a question or comment is said.

Throughout the book and the students' interactions with it, the language skills needed to become a competent, independent adult are taught and practiced. We are truly hoping that materials like this will help develop the character qualities that will build successful adults who use AAC from the children who use AAC today.

Kevin Williams==-paper
Bill Adams--paper

Public Interactions
(Part of Community Interaction at the University Panel)

Beth Anne Luciani

I don't know if I am one of the right people to be up here speaking about this topic. I know most people would call me an inadequate user when it comes to my DynaVox. Most augmentative communication users speak with their devices all day, every day. I am not that kind of user because I don't want to be.

If you would ask me what my natural voice was, my answer would be my eye gaze, and not my DynaVox. I use eye gaze every day with my family. I never use my DynaVox at home because it slows me down. My family, especially my mom, can understand me a lot faster than typing what I want to say on my DynaVox. When I go out with my mom, I never take my DynaVox. First of all, it gets in the way when I eat or do transfers. But most of all, I don't need it because my mom can understand me a lot better without it.

I know most of you sitting out there would like to say a few things to me right now. Say and think whatever you like, but you don't live my life. I know what works best for me, so I am going to use my DynaVox when I absolutely need it. That may be a few days a week, or that may be a few days a month. Whatever it is, it is my choice, and it is what I know I have to do. I don't like when speech therapists and other professionals tell you that you should use your device every day for everything. They think that is the right thing for a person, but maybe it isn't. Only the user knows what is right for him or her.

All right, I know I have probably made a lot of you mad at me, so I am going to move on to the topic. I am a fifth-year creative writing major at California University of Pennsylvania. I only take two classes a semester because of the workload. At the end of this spring semester, I had a 3.68 grade point average with 64 credits. This means I am a little over halfway finished!

Of course, I use my DynaVox at college. I would be lost without it. My mom is my attendant, but she only takes notes for me and tends to my needs. I answer questions in class. Most of the professors understand about my DynaVox really well and have no problems with it. Some don't understand about it, but they will accommodate it. They know it is how I communicate, and after I explain how it works, most of them are very patient with me.

Since my major is creative writing, I have to take a lot of English classes. The English department has taken to me, and the head of the department really likes me. They have no problems with my DynaVox. They know to be patient if I want to say something or ask a question in class. Some professors don't always understand what I say. If that is the case, I will say what I want on my DynaVox, and if they don't understand, my mom will repeat it for them. Usually, if I have had the same professor in

the past, he or she knows me well enough and has no problems with my DynaVox. In fact, one professor who I had for a writing class in the Spring knows me really well because I had been in one of her classes before. She knows about my DynaVox and to wait as I type my message. She is so good with it that she knew when I was typing a message during class. She would continue to teach while she kept looking over at me. When I looked up and nodded at her, she knew I was ready to speak. That was really nice because I didn't have to worry about getting her attention when I wanted to say something.

The students at college never have associated very much with me. I have no friends from college, and that is something I have learned to accept. It just goes with the territory. Some students are intrigued by my DynaVox and will come over and ask what it is. I happily show it to them and tell them how I use it. But some students think I play games on it during class. First of all, I don't even have games on my DynaVox, and, second, I wouldn't play them during class even if I did. Anyway, that is about the extent of my interaction with students at college. They don't bother with me because they either don't understand or are just plain ignorant. I have learned not to care because if they are indeed that rude, then they aren't worth my time.

I know I said that I don't take my DynaVox when I go out with my mom, but I do take it with me when I go out with my friends. I have two very close friends whom I go out with by myself a few times a year. Both of them have known me for a very long time – one for 21 years. Even though they know me and can understand my eye gaze pretty well, I take my DynaVox because it is faster. We usually have talks when we are together, and it is faster for me to use my DynaVox to have long conversations with them. Also, if they get stuck and can't understand me when I use eye gaze, I have my DynaVox right there to help me.

I feel it is essential for me to use my DynaVox in those kinds of settings or with those kinds of people. I have never ordered food by myself when I am out at a restaurant because I feel it is more work than what it is worth. I can hear the waiter now – "What? What did you say?" Five minutes later and having to repeat myself ten times, he might get the order right.

I am slowly striving towards independence, though, so all of the things I don't do now I would do if I had to. It is not like I am against using my DynaVox in every day life because I am not. It is just that I don't need it for everything in my life right now. If my life changes in years to come, which I hope it does, my DynaVox will be there for whatever I need it.

In conclusion, the point to my speech is my DynaVox is not my primary voice and I don't think it ever will be. Maybe that is wrong to some of you, but so be it. I wasn't born with a DynaVox attached to me, so I don't feel it is my natural voice. On the other hand, I am grateful that I have my DynaVox, and I use whenever I feel I need to. I realize that I need my DynaVox to communicate with people in this world, but I also realize which people I need to use it to communicate with.

On a final note, I would like to sum everything up with a few lines of a long story. On January 22, 2004, I was on stage with, sang to, and kissed by my favorite singer. After the concert, I met him. I literally had one of my biggest dreams come true that night! And I had decided to take my DynaVox because I had no idea what was going to happen, and I wanted it there just in case. Well, we got to the concert and my mom turned it on, and my switch wouldn't work. I couldn't use my DynaVox all night. Therefore, one of the times in my life when I really needed my DynaVox and had it with me, I couldn't use it! Think about this story before you ridicule me.

Thank you.

Bobby O'Gurek paper

Traveling with Disabilities

Sarah Lever: Consumer
Charlotte, NC

Abstract
I like to travel but, it isn't the easiest thing to do when you have physical disabilities and require adaptive equipment. I know that after twenty-six years of traveling with my family and colleagues. In this presentation I will share with you my experiences of traveling when I was very young up through my current age of 30 and the difficulties involved.

Thank you for asking me to this wonderful conference. It is wonderful seeing everyone here, again. I will share with you: some of my background with augmentative communication (AAC), education, work experience, and the main topic which is traveling with a physical disability. Speaking with professionals and users of AAC is a major challenge. So, I will begin by giving you a brief history of my background.

I finished my college degree in Internet Design at Central Piedmont Community College in Charlotte, North Carolina. My work experience has been with: Prentke Romich Company, Temple University, and Pennsylvania State University. Locally, I am on the Consumer, Family, Advocacy Committee in Charlotte, North Carolina. We assist in the reforming of programs to help people with special needs. I love to travel to AAC conferences in the United States and other countries.

When I was a small child my grandparents drove my family to the beach each summer. Those were great times for us. My brothers were able to carry me with ease until I was 7 years old. Everyone was there: my brothers, sister, grandparents, uncle and aunt. It was a time for the family to be together. My grandmother took us to the amusement rides. That was a lot of fun for us. When I wasn't being carried, I rode in an over sized stroller. As I grew older and took longer trips I needed more support for myself and my complex assistive devices. The longer trips meant flying in airplanes.

I am going to move on to when I started flying for vacations and to conferences. Our family took a vacation to Disney World when I finish high school. After the airplane landed, I was waiting in my seat to allow everyone else to exit the plane first. Then the attendants would bring the small isle chair to get me off of the plane. My brother got off before me. He saw a woman leaving the airport in my pink wheelchair. He stopped the woman and asked her where she got the wheelchair. She said, "The airline gave it to me". He got it back for me.

Since that time I have had to fly a lot more. My less traumatic flights have been to and from Charlotte and Pittsburgh, USA. Even on one of these flights the attendants helping me board via the small isle chair, dropped me leaving one of my legs hanging over the armrest and my bottom in the seat. That hurt! No one even said, "Sorry". At least, so far, on these flights the damages to my wheelchair has been less than $300 each trip.

My first international trip was to the ISAAC 2002 Conference in Denmark. The conference was wonderful, but the traveling was a nightmare. We didn't ask for help getting me to the bathroom. On flights inside the USA, I would go to the bathroom before boarding, then wear a pad and go to the bathroom after landing. Well, when you are going to be in the air for 13 hours everything changes. The doctor gave me urinary catheters to use on the trip. Somehow this didn't work well, because when my mom put a blanket over me while I was sitting in my seat and emptied the bag, it was blood red. We called the attendant who was a nurse and she took a look and said," It's not too bad". Mother freaked and encouraged me to drink more. After we landed in Denmark, she took the catheter out. After a few days that problem cleared up. Then I had another medical

problem that I hadn't been bothered with in years. It was very difficult to get medicines that are simple, over the counter, like in the U.S.

When we got back to the United States my wheelchair was returned to me with only the frame intact. The back and many other parts were broken. It cost $3,000 to repair that chair. It never worked well again and soon had to be replaced. After many faxes and telephone calls I accepted the fact that the airline was taking no responsibility for the damage that incurred while the chair was in their care. Even after all this, I love attending the ISAAC conferences and being a part of that great organization.

I am going to move onto the publications about the experiences of traveling with a disability. My favorite publication about this topic was on CNN, Anderson Cooper 360 Degrees, there was a girl named Rasha. I contacted Rasha and she said "You can tell the people at the conference that the law says bathrooms should be accessible every where, but for airplanes it says accessible bathroom only need to be on the big 2 aisle airplanes. The problem is that most of the airplanes flying in USA are small ones and it's not fair to say there is no need for people who use wheelchairs to use a bathroom because it will cost the airline money. They would loose the space for 2-3 seats to make one large bathroom; I told him that the airlines should take off all bathrooms on the plane and add 15 more seats. Then tell all the other people to wear diapers because the airline wants more seats to make more money. So, the airlines are canceling all bathrooms!!!!! I don't wear diapers everyday because I can use the bathroom. But, when we fly to Israel every year to visit my grandmas and the flight is very long, 4-5 hours. Then we change planes and fly for another 12 hours. The bathroom is so small I can't fit in it with mom helping me."

Rasha goes on to say, "Last summer my diaper was dirty and it smelled bad. I couldn't fit in the bathroom so my mom could change me. My head hit the floor a hundred times. This upset me so much because if I don't change the diaper when it gets dirty or wet it gives me rashes that hurt a lot and stays for days. I hate to smell bad the entire trip. A flight attendant said they had a curtain and she closed the small curtain for us. Still it was not good because when mom put me on the floor to change me my hand was moving a lot and it caught the curtain and moved and opened it. I can't stop my hands from moving and mom was changing me, so she couldn't hold my hand. That was embarrassing, because people could see me every minute and they could smell the bad odor. It isn't a real bathroom with a door but just a curtain and it doesn't stop the bad smell."

"PLEASE, PLEASE, PLEASE tell everybody you know to help us and sign the petition at www.ucp.org   so I can take it to the White House because we need lots of signatures so we can change the law. Thank you", Rasha (Short film about Rasha)

The Air Carrier Access Act was passed by the congress in America in 1986. The Department of Transportation (DOT) was expecting to develop new practices that would ensure a person with disability would receive the same treatment as any other passenger.

The Air Carrier Access rules are setup for problems during traveling. There are a lot of barriers for people with disabilities to encounter while traveling. Many of the problems are simple to take care of with a ramp or elevator. The carrier can't refuse to transport a person with a disability.

Did you know? (USA)
- Did you know the airline must return the wheelchair to the person at the gate or wherever the passenger request? *(You need to state where you want the wheelchair returned before boarding.)*
- Did you know that when the airline disassembles a wheelchair, they are obligated to return the wheelchair to the passenger in the same condition that it was received?
- Did you know the airline doesn't need to take the batteries out of the wheelchair if the batteries are gel-cell?
- Did you know on two isle airplanes you should get seats on the inside row *(The people with the person with the disabilities can get up without moving everything, when booking you need to tell the agent)*?
- Did you know people with disabilities should fly on the big jets? *(They can't get the isle chair onto the express jets well enough to transfer the person with a disability)*

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Rewind, Pause, and Fast Forward
(past, present and future)

Dawn Seals
United Kingdom

Hi, my name is Dawn, and I am from Nottingham, England, the home of Robin Hood. Right now I'm a college student, but I would imagine the experiences I have had and the barriers I have faced are typical of many trying to find employment.

In the UK, the use of communication aids has recently started to increase. This, I think, has happened for a number of reasons. At their inception, these machines were brand-new technology: they were expensive and, in certain areas, had to be paid for privately. For a long time, augmentative and alternative communication (AAC) devices were financially

out of reach for many people who could have benefited from them. Although in some areas, government, health, and education services combined funding to assist with the purchase of communication aids, individuals have often depended first on personal therapists' embracing the technology. If your speech therapist wasn't interested in AAC, you didn't stand a chance. I've been lucky in that most of my therapists have been AAC specialists—the ones who weren't didn't give me any support, so I've had to be self-motivated!

From the age of two and a half until the age of twelve, I was educated at special schools. From age twelve to age eighteen, I split my time between mainstream and special schools. In England, our education system approaches special education needs differently than the US: we have special schools for students who need more help both physically and educationally, and mainstream schools for everyone else. Only over the last ten years or so have more disabled students been integrated into mainstream schools. One of the main reasons it has taken this long is the persistent idea that "mainstreamed" special-needs students will slow down the education of the other students.

I was finally given my first communication aid when I was ten years old. Before then, I had used gestures, limited speech and eye pointing to communicate. I also had a very basic symbol book. Sadly, it was so useful that it always seemed to end up at the bottom of my school bag, or lost completely! It was so frustrating having something to say but not being able to get it across. Come on, I'm a woman, and I have my opinions. Need I say more?

My family could usually understand what I was saying because they lived with me and spent a lot of time with me. They did have problems understanding me at times, though, especially if I suddenly changed the subject! They always interpreted for me, but sometimes it was plain that people didn't believe I'd actually said what my parents told them I had. Now, I know I'm a blonde, but I don't need people to make up thoughts for me!

In class, it felt useless trying to compete with the kids who could talk. Although we were supposed to put our hands up and wait to be asked, the ones who could talk always shouted out the answers! I couldn't even raise my hand properly, so what chance did I stand? I just took advantage of this lack of involvement and turned it into naptime, or zone-out time!

The British Health Authority provided my first talker when I was ten years old. I got it through a project that was set up to see how two youngsters would get on with a talker and weekly speech therapy. The project was to last for one year, and I was chosen to take part! Honestly, I had not encountered very many real AAC devices before then. Now and again, people showed me actual talkers like Chat Box and Liberator, but they always whisked them away before I had much chance to experiment with them. If I'd blinked, I'd have missed them entirely.

Having a talker was great, but people seemed to forget that I had to learn about the machine before I could use it. I had to learn where everything was on the device, and I had to learn to 'speak' by working through lesson plans. It seemed as though I was expected to know all this overnight! I used to get comments like, "Say something, Dawn!"

Not everyone at my special school liked my new talker—especially the teachers! During one lesson, the teacher took my talker off my chair. The classroom assistant put it back. They argued, moving the talker up and down like a yo-yo, until the classroom assistant got her way. I found this battle of wills amusing at the time, but thinking back on it, that teacher was trying to take away my voice! Another teacher hated my talker because the little printer on my machine always seemed to break down during her lessons. She referred to it as "that damned machine!" Of course, there are also those who think I should be permanently gagged, but that's another story.

When I was 12, I started going to a mainstream school part time. I was determined to succeed. Mind you, I could have been put off and discouraged, because before I started one of the teachers at my special school had told me I'd never make it in mainstream school! What a terrible way to boost a girl's confidence! On the other hand, it made me determined to work as hard as I could. "I'll show her!" I thought.

I was the first person to use a talker in the school, and overall I think they coped with me very well. The people there were supportive and I made quite a few good friends. I know I couldn't have done it without the support of the classroom assistant from my special school, who came along with me.

That September, I went to secondary school where things were very different. This school had other pupils who used a wheelchair, but again I was the first one there with a talker. For the first few months, hardly anybody talked to me. They were frightened of me, and that included the teachers! Nearly everyone talked to me through the classroom assistant and, if she wasn't there, they either ignored me or talked really slowly and in a loud voice, as if I was stupid or deaf. I guess they were looking at my blonde hair again. One teacher used to buy my classroom assistant coffee out of the vending machine just to stop her from leaving the building to get it. She didn't mind the gesture, but said the coffee was awful!

If my talker broke down people seemed to think they couldn't communicate with me. One of the worst times was when a supply teacher shoved his face right in front of mine, to talk to me. His breath smelled terrible! I tried to back away but, my chair was in a corner and I couldn't move!

In most of my lessons, I hooked my talker up to a computer to do my work. I was fully integrated and, the longer I was there, the better things got. However, when I was 15, I spoke to the careers advisor at my special school about what I'd like to do, namely, to visit schools and colleges and talk to students and staff about my experiences to help to pave the way for others. Unfortunately, he didn't know anything about communication

aids and any possible work I might get. Guess what? When I left, over 3 years later, he still didn't know anything!

I used my talker to take an English for Business exam and a Child Care GCSE. I had a scribe to read out the questions. I answered using my talker and the scribe wrote down what I said. I also took a Certificate of Achievement exam in mathematics.

I went into Post 16 at my special school and 6th form at secondary school but as I was no longer integrated, I didn't enjoy it. The courses were boring and, after two years of doing the same work, I couldn't stand any more. I couldn't face another year, so I left.

College brought with it a brand new set of problems. When I applied two years ago, I went for an interview to find a suitable course. I told the interviewers about myself, including what I'd achieved so far, and what I hoped to do in the future. I told them that I hadn't gone to the local special-needs college because I wanted a higher standard of education. They suggested a course called *Progression to Adult Life*, or PAL. I wasn't even in the group for a day before I realised that the standard of education there was way below what I'd been working at. I think at the interview they'd seen the wheelchair and blonde hair and thought, "No brain here, let's put her in this group!" I plucked up the courage to tell them that I didn't think it was for me. Then, they suggested I join a group doing office administration. I went along and really enjoyed it.

Instead of allowing me to change courses right away, I was told I'd have to wade gently into a new one, just to make sure it was what I wanted! Didn't I know my own mind? It took until after the half term break for me to be fully transferred. Fortunately, I caught up with the others and passed the course and its exam.

At the moment, I am working on a Certificate in Office Administration. Again, I've had a few obstacles to overcome. I'm the first disabled person using a communication aid to take this course, so nobody knew at first what to expect. I'd only been there a couple of days when, during a lecture, the tutor went round the group asking questions. I'd prepared an answer on my communicator with the speech turned off, and sat quietly waiting my turn. Unfortunately, I must have been wearing Harry Potter's Cloak of Invisibility or something, because when it was my turn, he totally ignored me!

To top it all off, a few days later, one of my tutors asked me (through my support worker, not in person) if I wanted to transfer to another course. The reason she gave was that the other girls in the group weren't accepting me! I think you can gather your own conclusions on that one.

My parents and I had a meeting with an advocate from the college to express how we felt about this discrimination and decide what we wanted to do. They wanted to give me a special timetable so that I was taught away from the rest of the group. I stuck to my guns

and said I wanted to stay on the course with everyone else. I decided to talk to the students in my group about my situation and my experiences, and since then I've had no problems. The tutors' attitudes changed, too, when they realised that despite my disability, I work hard and hand my lessons in on time. It exhausts me, but I'm determined to prove myself right!

I've recently passed a spreadsheet exam, and I'm waiting for the results of three other elements. Next year I'm hoping to complete a computer course. It has taken years of frustration, hard work, practise and broken fingernails to get to where I am now. I'm still learning all the time but I really couldn't have done it without the support I've received from home and speech therapy.

When I leave college, I would love to find a job. Being realistic, though, I think the chances of that are very slim. I don't know about you, but I think that there is a lot of popular ignorance about disability that stops us from achieving our potential. When I was at school, we were expected to take part in a work experience. I knew someone who worked for the Royal Mail Postal Services and asked if I could join his team. Apart from one incident where someone treated me like a baby, everything went smoothly. My friend, understanding my disability, had explained to his staff that I was just like them and didn't need any special treatment.

Pittsburgh, USA – August 2005

I've come to the conclusion that, if we want to move forward, we can't just sit back and expect everything to come to us. We need to dispel the myth that being in a wheelchair automatically means that we are stupid. One possible way of achieving this in the workplace might be talking to future colleagues about ourselves, our disabilities, and our achievements.

Processes: Getting a Job; Communicating on the Job

David Gault
United Kingdom

I have had my current job for six years. I work part time, two mornings a week as a support worker in a resource centre for adults who have learning disabilities. The salary I earn does not affect the disability benefits I am entitled to. I got the job really by being in the right place at the right time. I had been helping out the staff at the resource center with training sessions on disability awareness and the

manager said that they may have funds to take me on as a staff member. My interview was really informal and as I already knew that some of my colleagues were willing to help me with personal care needs, I did not have to worry about that side of things. I only work 3 ½ hrs at a time so it does not involve much of their time. The nature of their job means that it is not a problem for them to support a person who has disabilities. This would not be the case in a different workplace.

I am now considering applying for a completely different job with another organization and I have had to think carefully about the barriers I face.

Transport is a big one. There are two taxi owners in Invernness who can offer power wheelchair users transport. At present I have the journeys I need booked. Because of the high demand for these taxis, getting them at any other time is practically impossible. For example, I was asked to change the days I worked one week and I could not do it, because I could not get to and from work.

Personal care and assistance at work are huge issues for me. I need help with all areas of care, eating and drinking, using the toilet and taking medication, which are main problems at work. If I worked more hours or had a new job, I could not manage as I do now. The considerations would be a career of my own or support from an agency or organization. The cost would be high so the salary would need to be sufficient to enable me to do that. I feel this is a real barrier to me ever gaining a full time job. But I am learning about job coaching and exploring ways around this. I have had help from the Shirlie Project who advise on these matters.

Communication is another problem. On the whole, I cope well face to face using my Pathfinder, but recording information and reading instructions, memos etc., is difficult for me   This means there are duties of my current post I cannot carry out independently. I know that applying for a new job and answering questions at a formal interview would be quite hard for me. The idea of having a full time

job and carrying out the responsibilities that are expected sometimes seems out of my reach. This is my ambition, though, and I will try my best to achieve it.

Through my work and in my private life I have a lot of interaction with people in and around my community, from chatting to my son's friends when they call, to making and attending appointments with health professionals--to actively representing the voice of disabled people on local committees. I feel I am accepted as a valued member of the community whether it be as a parent at the children's school, a team member at work, or as simple as a friend or neighbor at home.
With improved access to all community buildings I have no problems going to banks, shops or cafes.   I am confident that using my Pathfinder, people can see past the disability, and I feel I am living as full a life as the next person. It takes some people longer than others to chat with me naturally and feel relaxed, but I always feel I win in the end. And that is as good a message as any to finish with. We should all be positive and enjoy life and keep trying till we succeed. We may need to think in small steps to overcome some of the barriers out there. But if I think back, opportunities now are so much better and we have to keep on moving forward. Hopefully we can all win in the end!!

Open Door and the Government System
Victor Valentic

When Bruce asked me to write about my own experiences with starting my own company and the government services, I could hardly say no to him. Some people in the audience may have heard me speak about my business in the past. Today's presentation will include recent developments in my business endeavors.

To begin, I would like to give a brief overview of my business. My business is called Open Door. Open Door is an accessible search engine for using the internet. The programming in Open Door includes drop down menus and many easy links within sites and between sites. Previously I have presented on how many challenges I faced getting recognized by employment agencies and funding sources that my ideas were valid and attainable. I had many communication breakdowns during this process, but they had nothing to do with using AAC! After about 3 years of frustrations and much perseverance I finally convinced the right people to believe in my plan and received some funding to start the programming for Open Door. I thought that my troubles were over, but no! It took me considerable time to find a suitable programmer. Unfortunately, the person that I offered the position to decided not to accept it! I was back looking for a programmer.

One year ago when I was looking for another programmer to work for Open Door, my government worker called my friend and me in to tell us the government was not going to give Open Door the original funding for a programmer. It took this worker 3 months to call me after I had explained that I still needed to hire a programmer. When I went in for a meeting with this worker I realized that to my horror this was the same government worker who gave me tremendous grief around funding for a laptop way back in 1997! My dumb luck!

After the meeting with my worker, I realized I needed to see a lawyer to fight the government's decision. The government's decision was to take the money for my business employee back and never help me ever again. My friend and I thought we could be able to go to a lawyer because it was not right for the government to take my business' money back.

In July of 2004, we saw a lawyer and explained to my lawyer what the government was trying to do with my business. My worker wrote a letter to me requesting me to give the money back to the government however, she typed the wrong amount. I was panicking because the amount changed from 15000 to 150000 dollars. After I received the letter, my lawyer wrote a letter to my worker to have a meeting with her manager, her, my lawyer, my friend and me. In August, we had a meeting with my worker and her manager. My lawyer asked them to clarify the wrong amount in the letter. My worker admitted the amount was wrong.

The government worker asked why I needed to hire a programmer. She asked why I couldn't do the programming for Open Door myself. I have the academic requirements to do the programming, but my accessing speed is too slow to make the programming a feasible option to do on my own. They told us the money should be used for an assistant to help with phone calls, etc, but not for a programmer. My friend told them I would need a special programmer to program Open Door's website. My lawyer also said that I would need the original funding reinstated to look for someone else to program the site. The next day, the manager called my lawyer to tell me the government changed its mind. Open Door could be able to keep the money and hire someone else.

In September, I had hired someone to work for my company. After the ISAAC Conference in Brazil, he started working four days per week and half days because I was a flexible boss. Open door's employee worked very hard for the time he was employed. In January, my friend, my employee, and I went back to the government and asked if the government could be able to give Open Door more money for Open Door's employee's salary for the next year and equipment that Open Door would need to go on line.

Six weeks later, the government made a terrible decision to turn down Open Door's request for more money to help my company out. I had to lay my employee off because Open Door didn't have any more funds to pay him and the federal government employment taxes. However, my employee would take his job back in a heartbeat because he liked working for me.

In April of 2005, my friend and I went to a conference about employment and disability where we met the director for the Ontario March of Dimes. She took some time to talk with me and my friend about my business. I was surprised that the director for March of Dimes was interested about my business idea. I believed her interest in my business idea was to help the people who are in March of Dimes.

Initially, this director thought I could send my business plan to someone who is in charge of the Ontario North for the Federal Government. However, I am living in the southern part of Ontario and that person was unable to help me to find some money for my business. After six weeks of email tag with that person who works for the Federal Government, I emailed back to the March of Dimes director asking for another solution to my problem of finding some money for my business. This director emailed back to me and wrote she might have another solution to my problem with finding some money for my business.

March of Dimes has a Business Development Committee and there are business members who have successful businesses in the community. The director suggested a man on this committee who could perhaps help me find some money for my business. I needed to update my figures for open door to go on line, then I could send my business plan to that man.

Meanwhile the chief operating officer of March of Dimes was working on a partnership with Qualilife and Bell Business Solutions. Qualilife is an accessible software firm and Bell Business Solutions is a subsidiary of Bell. Bell is a telephone company and in your country AT&T is a similar company to Bell. I needed to update my resume because my resume was outdated.

I remember the time when the local March of Dimes didn't want to help my business at all. I could not see why they didn't want to help my business because my business could help the people who are living in the March of Dimes' housing to access the Internet through my easy design pages. If my worker from the local March of Dimes had been in contact with the director of March of Dimes, open door might have come out in 2003. My mother used to work for the local March of Dimes; if she was still employed by March of Dimes then she could suggest to me

that I could have gone to the director of March of Dimes. There were too many ifs in this solution for me that I could have done to find some more money to help my business out. I don't have any more regrets about what I could have done with my business.

I don't know where Bell Business Solutions and Qualilife or my business is going to but I have a positive attitude towards new business opportunities. I realize that to make new business opportunities I should have opened my mind to these opportunities. The game of making new opportunities is a fine art to look at. We, people with disabilities, don't have many opportunities to have our own businesses. However, I feel that the biggest disability that I have had in this business adventure, is that I did not have access to funds for my business. The challenges have not been physical or communication based, but rather the challenge of having to work through the bureaucratic web of government. I suppose the other major challenge was to fight the attitudinal barrier that people don't believe that non-speaking, physically challenged individuals can indeed run a business.

I hope you learned something to help you and your own businesses out. You must never be seen to give up because you might have lost the opportunity to help your own businesses out.

Work is at Home and Home is at Work: The Benefits and Challenges of Telework

for Individuals Who Use Augmentative and Alternative Communication

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Introduction

For individuals who use AAC, participating in the workplace may bring special challenges with respect to transportation, technology access, and activities of daily living (McNaughton, Light, & Arnold, 2002). "Telework", defined as work activities that take

place outside the normal work setting and that are made possible by internet and telecommunication technologies , may be a promising alternative to traditional office employment. At the same time, there are concerns about some aspects of telework, including the possibility of social isolation and reduced opportunities for receiving employer feedback (Kurland & Bailey, 1999).

In this study, nine individuals who use AAC and who are engaged in telework employment activities participated in an online focus group discussion moderated by Tracy Rackensperger. Participants discussed the following topics:

- the benefits of telework employment
- the challenges to telework employment
- recommendations to employers and individuals who use AAC for improving telework employment outcomes

1. The benefits of telework employment

1a) Efficiency of working at home

> "My trip to the office is cut from an hour and a half to 30 seconds" (S)
> " I can present my knowledge to my students more precisely, it's better than teaching them face-to-face"(R)

1b) Flexibility of schedule

> "I don't miss receiving phone calls about personal matters, like medical calls, that go on during business hours"

> 1c) Financial benefits

1d) Relationships with co-workers

2. The challenges to telework employment

2a) Communication with co-workers

> " Communicating by phone or email loses the face to face interactions that many people need to establish trust" (F)

2b) Motivation

> "It is much harder to stay focused at home than it is at work"(J)
> "My working space and living space totally overlap and constantly interfere with each other" (S)

2c) Technical/Equipment issues

.3 Recommendations for employers

3a) Promote interaction with teleworker

> "Include (the teleworker) in conference calls and chatrooms, don't limit work to email"(S)

3b) Be flexible and accommodating as needed

> "It is important that the employer lets the worker be self-directed. Micromanaging works even less well when there is telecommuting involved."

3c) Provide a positive, inclusive environment for the teleworker

> "A boss needs to stick up for their telecommuting employees…they need to be sure the employee is talked about in a professional manner even when the employee is not there"

4. Recommendations for people who use AAC

4a) Clearly demonstrate your competence

4b) Be flexible but voice your ideas

> "Rather than demanding a certain set of conditions with no compromise possible, give the employer room to "dance" during some negotiations

4c) Develop strategies to be a successful teleworker

SUMMARY

Telework appears to provide a promising approach to employment for some individuals who use AAC. Participants identified clear advantages to telework over traditional office activities, including flexibility of scheduling and increased efficiency. At the same time, participants spoke of a need to be proactive in addressing challenges associated with telework, including developing techniques for regular communication with fellow workers, and utilizing strategies to ensure receiving regular feedback from the employer.

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Angie Monzon PAPER

Having an Impact with Technology
Paul Garrick

My name is Paul Garrick. I have been an augmentative speech device user for 15 years. Through these past years, I have worked with all kinds of AAC devices, along with many other operators.   I have used a Touchtalker, a Liberator, and am presently using and getting to know my third speech device, called a Pathfinder. Because of this experience, SHOUT has asked me to speak to you and tell you all about how I am affecting the community with my Assistive Augmentative Communication device.

In the past few days, the AAC field, engineers of speech devices, and Prentke Romich Company have had a great opportunity to get a lot of feedback from the great number of users that are here at this convention. If you look around this room, you will see that I am very lucky and one of the few speech

device operators who is not in a wheel chair. Therefore, I feel that I can give a lot of feedback from a different point of view.

The first large impact has been only a challenge to me. That impact was fortunate enough on my church community to be asked to be on the liturgy schedule. Now, a six hundred family church community that consists of family and friends supports me as a lector. Many people who had never heard of a speech device before are now familiar with how it works and how it can help a disabled person to communicate with others. If it was not for me being a lector, they would have never had this opportunity. While many people in my community have been receptive to my use of a Pathfinder, it sometimes gets frustrating for people to wait for me to type in my complete message. Often times people just ask me to write it down on a piece of paper. It is my hope that the ACC developers can find a way to speed up this process.

I have to carry the device around, which is different and sometimes difficult. I am hoping with all the improvements in modern technology, they will soon come up with a pocketsize device. That would be a great help as I will then be able to take it with me everywhere and not just when it is convenient. For instance my job, as a maintenance assistant: I do maintenance and gardening. It is very difficult to carry my Pathfinder around and even more difficult to keep it nearby. Therefore, communication can become difficult at times. This is a big problem communicating with coworkers or the community when I come into contact with them.

Another way that my Pathfinder has affected the community is that I am able to take an office in different organizations and become more involved in the community. If I didn't have the ability to speak and express my opinions, through the Pathfinder, this would not be possible. Again, speed and time can be an obstacle, but at least I have been given the opportunity.

Thank you for listening   And I thank all the individuals in the AAC field who are working so hard to improve on our future AAC device users, so that we may all have the ability to be more involved in our communities. They have come along way, but voicing our opinions as users will direct them where to go with technology in the future.

Communicating in Public Places

Randy Horton

My name is Randy Horton. Hi everybody. Using my Pathfinder in the community. My most recent experience was being the master of ceremonies at a fundraiser to dedicate an arena to a very special man Johnny Carpenter. I met him when I was 9 years old. He made me the advocate I am today! In my introductory speech I told about his Heaven on Earth ranch where children with disabilities learned to ride horses and have confidence in themselves. I said how his trust and support made me believe in myself. Kimberly and I were married at the ranch. I loved him and the ranch very much! After my speech I introduced 8 acts including a woman whose songs are performed on TV on She Gets What She Wants a group that does jazz rhythm & blues and Carribean calypso with the steel drum and a Korean hand bell team. Would you believe that the program director asked me to announce the acts from way off to the left of the stage?   I said hell no! in a very polite way of course, and took center stage, each time to introduce each act.

A place where, using my Pathfinder in the community literally saves my life is my messages about my leg bag. I have them stored in an activity row. I can instruct a total stranger, telling him to please help me in the restroom. I tell him what to do, step by step. If the system is blocked, it must be unblocked immediately, or I can end up hospitalized.

Another place where an activity row is a life-saver, is when I need to insist that my chair be tied down when I ride on public transportation. I tell the driver politely, at first, what needs to be done. If the driver does not heed my directions, I say, "Company rules say that it is your responsibility." Then if there is still no compliance, I say, "You need to call your supervisor," Followed by, "All right I will call them myself." And, "Please send a supervisor," if the driver refuses to tie my chair down.

I have used my device to be an advocate many many times. For example I flew to Sacramento to give the Terminator, "Awhnold," a piece of my mind for proposing budget cuts. I said, I oppose the budget cuts that the Governor has proposed to DDS and IHSS. They would severely impact not only the quality of my life, and that of my wife Kimberly, but could endanger our health and safety as well. I detailed what the cuts would mean to all of us. Then I concluded, forty years ago California made a promise to people with developmental disabilities when the Lanterman Act was passed. Our independence dignity and very lives are now in your hands. Keep the promise. Vote against these cuts! I went to Sacramento so many times that I got a free airline ticket for Pec, this year.

Finally I really enjoy working the booth for PRC. I show people, in detail, all the bells and whistles on the Pathfinder. Julie Fabrocini the beautiful actress who has a son with CP, came by one time and I had a long talk with her. That was fun!

Being part of this panel was fun too. Thanks everybody, for listening.

Employment and Community!

Leigh Ann Lightholder

In order to be interacting within my community and to be employed like everyone else, we have to start somewhere and a great starting point is at home. My first thought of writing this speech to present to you today is how could I write something about employment and community interactions? Actually, I am not employed. No matter how hard I try and no matter how many conferences I have attended, I am still trying to become employed.

So I'm not employed, but I am somewhat of an employer. Here's how it goes. I had a friend who was my personal care aide. He became very ill and had to quit. Now what do I do? I called United Cerebral Palsy and they told me that I needed to place an ad in the paper to advertise for a new aide. I preferred to have a private individual rather than an agency providing personal aides for me. This was a first for me. After the ad was placed in the paper, I received 4 calls. I set up the interviews and started the process of finding the perfect person In the meantime, my mother asked a former co-worker to help out. Debbie who worked with my mother was helping out until I filled the position. Before I was able to fill the position, Debbie came to me and told me that she decided she

would like to stay on as my personal attendant. Another decision needed to be made. I had two out of four people coming to be interviewed and now I had to decide what to do. After I interviewed the two women, I explained that I only needed a backup or a person to take care of me in the morning until Debbie could get there. Debbie lives about 1 hour from me. They both were interested so I picked the one that seemed like she wanted to be involved in my life and she lived close by. I know there are a lot of us who have personal aides, but did you every think that you were the one who made the decisions just like a boss? Maybe I don't have a job, but in order for my aide to have a job there must be people who require assistance. I guess you could say I am a commodity in the chain of life.

    In the course of a week, I have many different activities and I also do some volunteer jobs. I am a Pittsburgh Ambassador and we meet once a month. The lead Ambassador, Jennifer Lowe, corresponds with the other ambassadors via e-mail or calls them. Since I started with the Pittsburgh Ambassadors Program, I feel I have gained confidence in myself. Sometimes when Jen needs help or something comes up, she will turn to me to see if I can help out. I am also involved in my church. I am one of six elders. I serve at the Lord's Table. I use my device to say a blessing for the cup or the bread. Another job at church is being the chairperson for missions. My job is to organize different members to present the minutes to missions along with me once or twice a month. A minute to missions is a short little speech about how we can support the different missions throughout the world each year. I also help with the Sunday school program with the children and make sure that the needs of the special needs children are met and taken care of.

    So being employed and bringing in an income is not always necessary to keep one self busy. I am involved with the community through the ambassadors program and through my church. I am someone without a job and my mother always tells me I am retired and she wishes she were too. There are people like me who wished they could get a job and then there are people out there that have jobs and they wish they didn't have to get up everyday and go to work. So go figure.

    What I am trying to get through is that if we don't have the help or the assistance for ours needs, we may not be capable of being employed. Thank you to the people out there those are willing to do things that we aren't capable of doing for ourselves. I know that since I got my attendant care, it has made my life a bit easier and more enjoyable because I now have a friend who cares about seeing that my needs are met. Maybe some day I will get a job and be more involved in the community. Thank you.

In Hospital Without AAC: Involving Carers in Interaction and Support

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When a person with disability enters hospital and does not have access to their usual AAC system, he or she may rely upon the support of a family member or friend to communicate. These unpaid carers provide valuable care and support, and may also create a way for the person with disability to interact more successfully with hospital staff. In this paper the authors describe how unpaid carers see their roles in care and communication support in hospital, and what they think would help the hospital experience for all involved. Results of focus groups that included a) people with complex communication needs; b) hospital and disability support staff; and c) unpaid carers; talking about hospital experience and the roles and needs of the unpaid carer will be summarised. The authors will draw upon the stories of the carers, people with complex communication needs and hospital staff to highlight ways for people with complex communication needs to prepare for communication and interacting with hospital staff and unpaid carers in hospital.

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