Pittsburgh Employment Conference

FOR AUGMENTED COMMUNICATORS

FOCUS ON JOBS

August 5-7, 2011

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of the

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Pittsburgh Employment Conference
for Augmented Communicators

PEC@ 2011

August 5-7, 2011

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SHOUT PRESS

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Biennial Pittsburgh Employment Conference
for Augmented Communicators
PEC@ 2011

Theme: Focus on Jobs

8:00 - 9:00 a.m. •• Registration and Continental Breakfast ••

Friday, August 5, 2011 First Day

9:00 a.m. Opening and Recognition
John L. Bernard, M.Ed., CRC, President, SHOUT
Retired District Administrator of the Pennsylvania Office of Vocational Rehabilitation
Hickory, Pennsylvania
Bruce R. Baker, *L.H.D.* (*Hons. causa*), PEC@ 2011 Chairperson
Pittsburgh, Pennsylvania

9:05 a.m. The Theme of PEC@ 2011:
Employment: *Focus On Jobs*
Jennifer Lowe, Executive Director, SHOUT
Pennsylvania Training and Technical Assistance Network (PaTTAN)
Pittsburgh, Pennsylvania

9:30 a.m. Higher Education Leads to Higher Success
Beth Anne Luciani, B.A.
Creative Writer
Editor, Newsletter, Pennsylvania Developmental Disabilities Council
Board Member, SHOUT
Monessen, Pennsylvania

10 a.m. Employment: Social Capital Can Be Your Friend
Jeff Parker, B.S.
Chief Operations Officer
UCP/CLASS - United Cerebral Palsy of Pittsburgh
President, Three Rivers Community Foundation
Pittsburgh, Pennsylvania

10:25 a.m. The Speaker Circuit as the Road To Employment
Chris Klein, M.Th., Executive Director
Clay Vessel Inc.
Holland, Michigan

10:50 a.m. **Break**

11:05 a.m. Developing and Supporting Leadership Among People Who Use AAC
Faye Warren, B.A., Chair, PWUAAC (People who Use AAC)
ISAAC Board
Ocoee, Florida
Sarah Lever, A.A.
Avon Representative
Charlotte, North Carolina

11:30 a.m. Twenty Years of Full Time Employment: A Lifetime of AAC
Richard D. Creech, M.S.
Pennsylvania Training and Technical Assistance Network (PaTTAN)
Harrisburg, Pennsylvania

12:00 Noon **Lunch**

1:15 p.m. Long-Term Employment in a Project Benefiting People with Speech Difficulties:
How Speech-to-Speech Can Facilitate Telephone Conversation for AAC Users
Bob Segalman, Ph.D., Sc.D. (*Hons. causa*)
Founder of Speech-to-Speech
President, Speech Communications Assistance by Telephone, Inc.
Sacramento, California

1:40 p.m. Situations and Strategies in Higher Education &
Greetings From the President of USSAAC
India Ochs, Esq.
Attorney and Social Justice Advocate
President, USSAAC
Annapolis, Maryland

2:05 p.m. Employment and Communication Performance
Katya Hill, Ph.D.
AAC Institute
Associate Professor, Communication Science and Disorders
School of Health and Rehabilitation Sciences
University of Pittsburgh
Pittsburgh, Pennsylvania

2:35 p.m. People First of Ohio, an Advocacy Group for Disability
William Adams, B.A.
Vice President, Board Member, People First of Ohio
Portsmouth, Ohio
Sadie Hunter
Executive Director
Columbus, Ohio
People First of Ohio
Joellen Hunter
Advocacy Director
People First of Ohio
Columbus, Ohio

3:00 p.m. Presentation of The "Joe" Award – Pensé Productions -- Trailer
Presented by Eric H. Nyberg, III, Ph.D.
Professor
Language Technology Institute
School of Computer Science
Carnegie Mellon University
Pittsburgh, Pennsylvania

3:15 p.m. Break

3:30 p.m. Two AAC Professionals Experience Temporary Communication Disabilities
Susan Balandin, Ph.D.
Professor, Faculty of Health and Social Care
Mold University College
Norway
Bruce Baker, *A.M., L.H.D.*
Adjunct Associate Professor
School of Health and Rehabilitation Sciences
University of Pittsburgh
Pittsburgh, Pennsylvania

3:55 p.m. Don't Feel Like an Unmarked Paper Bag -- Some Job Tips
Snoopi Botten
DECtalk Musician
Niles, Ohio

4:20 p.m. Why We Are Having a Play Tomorrow
"Step by Step," CBS Morning News
Gregg Mozgala, BFA, Actor, Writer, Dancer
New York City, New York

4:45 p.m. Getting Ready to be a Grown-up: Jobs and Teens
Robin Wisner
Consumer Advocate
AAC Institute
Board of Directors
Always On Our Own

Caleb Hurd, 8th Grade
Joshua Hurd, 8th Grade
Fairview Middle School
Erie, Pennsylvania

5:15p.m. Closing of Day One

7:15 – 8:15 p.m. Documentary Night – "Only God Could Hear Me"
•• It is free to all conference registrants ••
MAIN CONFERENCE ROOM, SHERATON STATION SQUARE

Saturday, August 6, 2011 Second Day

8:00 – 9:00 a.m. •• Continental Breakfast ••

9:00 a.m. Life on Life's Terms: Living As An Augmented Communicator
Panel Discussion Leader:
Kevin Williams, B.S.
Charlotte, North Carolina
Panel Participants:
Ami Profeta
Elkins Park, Pennsylvania
Paul Garrick
Scott Township, Pennsylvania
Jennifer McIntosh
Keene, New Hampshire
Jessie Jackson
North Wilkesboro, North Carolina

9:30 a.m. Running My Own Business
Brad Whitmoyer
Delaware, Ohio

9:55 a.m. The Rights of People with Communication Disabilities in Traveling
Richard Devylder
Senior Advisor for Accessible Transportation
U.S. Department of Transportation
Washington, D.C.

10:20 a.m. A Tribute to James Prentice
Al Condeluci, Ph.D.
CEO
United Cerebral Palsy Association of Pittsburgh
Pittsburgh, Pennsylvania
Don Jones, B.A.
Board of Directors, SHOUT
Wilmerding, Pennsylvania

10:45 a.m. Break

11 a.m. French Twist – a play by:
Gregg Mozgala, BFA, Actor, Writer, Dancer
New York City, New York
Starring: Kevin Williams, Tourist
Gregg Mozgala, Tourist
Cre Engelke, Waiter
Elizabeth Pegg, Louise, Potential Girlfriend

11:30 a.m. Living with a Disability: Owning My Own Business; Being an Entrepreneur, Being a Mentor to Other AAC Users
Panel Discussion Leader: Chris Klein, M.Th.
Executive Director, Clay Vessels
Holland, Michigan

Panel Participants:
Luis Ross
Phoenix, Arizona
Daniel A. Shirey
Natrona Heights, Pennsylvania
Robert O'Gurek, A.A.
Schnecksville, Pennsylvania

12 Noon Lunch

1:15 p.m. **Town Meeting – "Focus on Jobs"**
Meeting Leader: Jennifer Lowe, B.A., Executive Director, SHOUT
Pennsylvania Training and Technical Assistance Network (PaTTAN)
Pittsburgh, Pennsylvania

2:30 p.m. Raising the Bar for Vocational Opportunities &
Greetings from the President Elect of USSAAC
Patricia Ourand, M.S., CCC-SLP
President Elect, USSAAC
Baltimore, Maryland

2:55 p.m. Finding a Job
Kathryn May, B.S., ATP
Texas TERA (Technology Empowerment Resources and Advocacy)
Round Rock, Texas

3:20 p.m. Jumping Over Hurdles to Maintain a Job
Gus Estrella
Phoenix, AZ

3:45 p.m. Out and About: Using a Communication Aid at a 7-11, at an Emergency Room, and on a Date
Bac Shelton, BFA
Ambassador and Consultant, Prentke Romich Company
Dallas, Texas

4:15 p.m. European Examples of the Participation by People with Disabilities in Employment and Political Life
Søren Vintergaard
Speech-Language Pathologist, Kommunikationscentret
Copenhagen, Denmark
Cristina Larraz
Speech-Language Pathologist
Centro de Referencia Estatal de Autonomía Personal y Ayudas Técnicas
(National Centre for Personal Autonomy and Assistive Products)
Barcelona, Spain (Catalonia)

4:40 p.m. Greetings from ISAAC International Leadership
Franklin Smith, MBA, CMC
Executive Director, ISAAC
Toronto, Ontario
Faye Warren, B.A.
Executive Board Member, ISAAC
Ocoee, Florida

5:00 p.m. **••• Closing of Day Two •••**

SHOUT Dinner/Picnic -- 6:00 p.m. to 9:30 p.m. (All registrants invited)

Location: 1000 Killarney Drive, Pittsburgh, PA 15234
*Directions: Accessible transportation is available to through Port Authority Transit – go across the street from the Smithfield St. Bridge (Take trolley going into the South Hills, get off at the **Killarney Drive** Stop – You may also arrange, in advance, for private ACCESS Transportation, 412.562.5353*

Sunday, August 7, 2011 Third Day

8:00 – 9:00 a.m. •• Continental Breakfast ••

9:00 a.m. Two Men Discuss the Role of AAC in their Lives

How AAC Helps in Achieving Independence
Todd Hutchison
Hutch Snack & Co./Hutch Gift Shop
Buffalo, New York

A Little Laughter Along the Way Helps
Paul Pecunas
Erie, Pennsylvania

9:25 a.m. My Experience in Schools
Victor Valentic
Hamilton, Ontario
Canada

9:50 a.m. Work and Attendants: A Double-Edged Sword
David Chapple, B.A., Beta Tester / Remote Troubleshooter
Prentke Romich Company
Editor, AAC ConsumerNet
Board of Directors, AAC Institute
Ravena, Ohio
Jennifer Lowe
Executive Director
SHOUT
Pennsylvania Training and Technical Assistance Network (PaTTAN)
Pittsburgh, Pennsylvania

10:20 a.m. British Benefits, Social Services, and Employment: The Dilemma for AAC Users

Peter Zein
Hembay, Kent, United Kingdom

10:45 a.m. ISAAC 2012 Conference Chairs Tell Us about the 15th Biennial Conference of ISAAC in Pittsburgh, Pennsylvania!

Katya Hill, Ph.D., CCC-SLP,
Associate Professor, Communication Sciences and Disorders
School of Health and Rehabilitation Sciences
University of Pittsburgh
Pittsburgh, Pennsylvania
Søren Vintergaard
Speech-Language Pathologist, Kommunikationscentret
Copenhagen, Denmark

11:15 a.m. Living with Disability

Robert Watson, M.S.W.
Executive Director
DateAble, Inc.
Brandywine, Maryland

11:50 a.m. Closing Ceremonies

David Bostick, MEd., CRC, Board Member, SHOUT
Retired Supervisor
Pennsylvania Office of Vocational Rehabilitation
Pittsburgh, Pennsylvania
Jennifer Lowe
Executive Director
SHOUT
Pennsylvania Training and Technical Assistance Network (PaTTAN)
Pittsburgh, Pennsylvania
Bruce R. Baker, *L.H.D.* (*Hons. causa*), PEC@ 2011 Chairperson
Pittsburgh, Pennsylvania

••• 12:00 Noon -- End of Conference •••

Next Conference: August, 2013

PEC@2011
Employment: Focus on Jobs

Platform Presentations

Day 1

Obtaining and/or maintaining employment for augmented communicators and/or individuals with significant speech disabilities was and might always be challenging. As you have heard, I made the choice to maintain being employed, even though, my SSI benefits were cut significantly. My benefits have become only a few dollars plus an insurance card. This insurance card has proven to be invaluable! … Working provided me with a purpose and boosted my self-esteem immensely!

Now, let the conference begin!

("Choosing to Work" – Jennifer Lowe)

Choosing to Work

Jennifer Lowe, B.A.
Executive Director
SHOUT
Pennsylvania Training and Technical Assistance Network (PaTTAN)
Pittsburgh, Pennsylvania

There was a married couple. The people both had Cerebral Palsy: with the wife with having more capability. The wife could talk more intelligibly and had the capability to walk. The wife worked every day at the mail office while the husband stayed home. The husband sat in a chair and also talked but his speech was much less intelligible. This husband played on the computer while his wife went to work. This arrangement enabled the couple to retain their Social Security Income. This was sad because the husband had to sacrifice being a productive part of society in order to keep collecting SSI. This was a ridiculous choice to have to make!

We are focusing on jobs this year. What does that mean? In the years passed, The Pittsburgh Employment Conference had a theme of jobs. Some might argue that this should be the focus of every one of these conferences. After all, it's in the name.

The problem has been that for the augmented communicator, the prospect of obtaining and maintaining a gainful position was a challenge. Augmented communicators may have had the desire for a job but outside circumstances have made it virtually impossible. Due to that, many individuals have relinquished the notion of being employed.

With me, I made the choice to work. As you might know I work for an organization called PaTTAN. The acronym PaTTAN stands for Pennsylvania Training and Technical Assistance Network. Pittsburgh PaTTAN has been affiliated with the Intermediate Unit 1 with the Board of Special Education. While I was at a SHOUT networking event, a woman who I knew from my school days introduced me to a woman who was the head of Pittsburgh PaTTAN. This was how I was hired at the Pittsburgh PaTTAN seven years ago.

The PaTTAN boss, when I was hired, worked with my unique requirements. The Office of Vocational Rehabilitation required me for at least, 12 hours per week. The other unique challenge I had was the time that I started my day. It was negotiated that I would start my day at 12 o'clock and work until 4 o'clock. Since PaTTAN enabled their workers to work from home, I took advantage of that option once a week. My reason was this would enable me to have a break from having to take Access Transportation for three consecutive days. Actually, I felt fortunate that PaTTAN was willing to work with me like this.

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In the very beginning, working at PaTTAN was exasperating because I didn't have a set job. First, I created assistive technology newsletters which consisted of looking at special A.T. web sites and cutting and pasting the new information on to a document. I did two of these for all three editions. Second, I went through web sites and determined whether they were active or not. I compiled this information into a document. My third assignment was very similar to the second but this time it was for the deaf blind project. In other words, I had several assignments that I felt like I was under utilized. From word of mouth, was how my job improved.

Working at PaTTAN had a positive side which was my colleagues. Most everyone has been so nice to me. Occasionally, I was able to provide assistance to a colleague. When a colleague would come to inquire my opinion on a non-speaking child, I enjoyed providing my insights. This invigorated me because it felt like I was benefiting others which were my entire goal of working at PaTTAN. Those were my shining moments which provided me the desire to continue working there.

Recently, a colleague videotaped me delivering a presentation. The presentation was my Communication Evolution. Then, I answered questions to help teachers help disabled students with significant disabilities. This felt so rewarding to benefit other education professionals! My colleague wrote extra questions for me to answer on videotape. Although it made me acknowledge that I was older, the fact that my experiences and my insights were actually impacting other Special Education teachers was incredible!

Up until now, I have neglected to talk about my obvious job, as The Executive Director of SHOUT. There was a reason for that. No, it wasn't because my SHOUT position was less important or less meaningful. In fact, being The Executive Director of SHOUT proved to be more meaningful than being a consultant for PaTTAN because I've worked for my passion. My ultimate passion was always to benefit other augmented communicators! The mission of SHOUT is to educate and to advocate for non-speaking individuals who rely on augmentative communication to obtain employment, enabled me to do just that! Being The Executive Director of SHOUT, I have sincerely helped other augmented communicators realize their goals. That has been amazing!

As The Executive Director of SHOUT, I have been organizing a component of the ISAAC conference. ISAAC 2012 will be held in Pittsburgh, Pennsylvania! This has been so rewarding too! Choosing individuals to be on the planning committee was the initial task. My partner was Faye Warren. It has been a major undertaking!

My position has evolved over years as the Executive Director of SHOUT. Initially, I would attend several fund raising meetings. With the economy like it has been, I did this increasingly less. This year, I have concentrated on promoting PEC at PaTTAN, primarily.

Obtaining employment for augmented communicators was and might always be challenging. As you have heard, I made the choice to maintain being employed, even though, my SSI benefits were cut significantly. My benefits have become only a few

dollars plus an insurance card. This insurance card has proven to be invaluable! This choice was the opposite from the man that I illustrated in the beginning of this presentation. Working provided me with a purpose and boosted my self-esteem immensely!

Not every augmented communicator, even just a person with a disability has made the choice of working. They ask why they should work when they make more on SSI. While I can understand that thinking, I think it's sad. Working provides a person with a purpose, self-esteem & a routine. Working has more value than remaining home collecting the maximum SSI.

Higher Education Leads to Higher Success

Beth Anne Luciani, B.A.
Creative Writer
Editor, Newsletter, Pennsylvania Developmental Disabilities Council
Board Member
SHOUT
Monessen, Pennsylvania

Good morning! It is an honor to be the lead speaker of the conference again this year! I never imagined my speech from two years ago would have the success and the overwhelming positive feedback as it did. I guess honesty really is the best policy!

Most of you have followed my journey through college for 10 ½ years. I am very happy and proud to say that I finally graduated on May 7th of this year! Except that it was cold and raining, it was a bittersweet day. Ten and a half years of my life, and a lot of hard work, made me accomplish one of my biggest dreams. As my name was read and my mom pushed me across the stage to receive my diploma from the president, the entire faculty on the stage applauded for me. It was a moment I will never forget! Not only did my family and friends know what I had accomplished, but so did they.

It might have taken me 10 ½ years to get a degree in Creative Writing, but it was all worth it to me. To have that piece of paper was more than an achievement. It was the first real dream I had accomplished in the outside world as a person with a disability.

Along my journey, I was ridiculed, doubted, and blatantly asked why I was going to college. I guess people assume if you are handicapped, you shouldn't go to college. I say, "Why shouldn't you?" If you know me well enough, you know I never do anything because of my disability. I also never do anything because I want to be a role model. I do everything in my life for myself. I have never and will never put my disability first in my life. I wanted to go to college since I was young, so I did. My disability wasn't going to stop me. If I lived my life with my disability first, I would get nowhere. I wouldn't have done half of the stuff I have done so far.

My drive to attend college was because I wanted to go further in life and be successful. I went to The Day School at The Children's Institute for 16 years. The Day School is in Pittsburgh, and it is one of the top three leading schools in the country for students with disabilities. Even though I was the highest functioning student in the school, my education lacked a lot because I needed intensive physical, occupational, and speech therapy. I knew when I graduated from The Day School, I had to go to college. I had to do it to get what I wanted out of life. If I wouldn't have gone to college, I wouldn't have the knowledge I have today. I wouldn't have taken advanced classes and be the writer I am today. I was never pushed to go to college. It was always something I wanted to do and never thought twice about.

I am not saying college was easy, but I am not saying it was impossible, either. I had struggles like the average student. I had to be tutored for seven semesters before I could take the math placement test. That was really fun! Still to this day, I can't do much above pre-algebra. It doesn't bother me because I know math has never been my strong point. Writing has always been my strong point, so that is what I focused on, and why I chose to be a Creative Writer.

Aside from taking tests separately from the class because I needed extra time, I can honestly say I asked a professor only once in 10 ½ years to adjust an assignment for me. It was because I was having severe back pain and knew I couldn't do all the writing required. California University of Pennsylvania doesn't believe in adjusting the curriculum for students with disabilities. I feel that is the way it should be because I got the same education as everyone else. Although it is true that I didn't ask for special accommodations, the professors from the English department who got to really know me would give me extra time to write papers, and some of them would even e-mail me tests to take at home.

The hardest part of being in college wasn't the work. It was being ignored and feeling like an outcast. I can honestly say I have no friends from college. It bothered me until about my fifth year, when I realized that if people didn't want to talk to me, then I didn't want them as friends. For me, college wasn't about making friends; it was about getting an education.

As I said, I wanted to go to college because I wanted to be more successful in life. That has happened more than I could have imagined. Some of you may have seen the video about me succeeding at college at the conference in 2007. David McNaughton, a professor at Penn State University, made the video about me because he thought it was rare that a person who used AAC was going to college and was successful. He wanted to show people this was possible. Since then, I have worked with David every semester. He shows my video to his classes. The students watch the video and write questions for me to answer. He e-mails me the questions and I pick the ones I want to answer. In turn, he pays me for answering the questions and royalties for showing my video. I didn't ask for any of this. I made the video because I wanted people to know that people with disabilities can go to college. I didn't want to be a role model. I just wanted to show people that I was living my dream and how people with disabilities can succeed with the right techniques. I don't feel like I am a role model, but when people see my video, I feel like I am helping them. That is why I do it. If I have helped even one person realize that he can do what I did, then I feel I have achieved my goal.

I have had another job for three years now. Tina Calabro, who has a son with cerebral palsy and writes articles about disability awareness for the Pittsburgh Post-Gazette, met me while I was still at The Children's Institute. Her son would go there to get different therapy. I honestly don't know what gravitated her to me, other than the fact that I would go through halls and everyone knew me. After I graduated from The Children's Institute, we kept in touch through e-mail. She knew I was going to college to be a writer, and she

obviously knew that I was intelligent.

Three years ago, she wrote me out of the blue with a job opportunity. It was editing a newsletter four times a year for the Pennsylvania Developmental Disabilities Council. While I knew I wrote well, I had no experience with editing. But editing was actually something I was interested in and thought about doing after college. Therefore, I took the job, and Tina agreed to mentor me through the first few issues. The mentoring helped me immensely because Tina taught me that I was in control, and I could change anything that didn't make sense to the average reader. Honestly, it is surprising how poorly professional people write.

It has been three years, and I still have the job with the Pennsylvania Developmental Disabilities Council. I love it, although I still have trouble with doing the layout, but that is another story! I love doing the editing and knowing that the final changes are almost all mine. It is like painting a masterpiece and having everyone see it four times a year. Although I have never met a single person on the Council, I am well-respected. I have met my boss, so to speak, and she is wonderful. She knows this is my first editing job, and if I need help or make a mistake, she is patient with me. Through Tina's confidence in me, and the experience I have gotten through the job, I feel I have become a really good editor.

With working for David and the Pennsylvania Developmental Disabilities Council, I feel people respect me because of the knowledge I have. I don't think I would have gotten either job if I hadn't gone to college. As I said, I didn't have the proper education when I graduated from The Children's Institute. There is no way I would have been able to edit a newsletter if I didn't go to college. Getting that education has helped me in so many ways. People see me as a professional writer and have respect for what I can do. I don't feel my disability comes first to these people. It is my knowledge, degree, and professionalism that they see.

I once heard a professor tell a group of people with disabilities that they didn't need to go to college because it is who you know and not what you know. That statement angered me so much because it isn't true. Yes, people can have skills, but skills can take you only so far. If you do the same routine every day, you aren't learning anything new. College gives you opportunities that you wouldn't imagine. It isn't only about the learning; it is about the experience. I had an internship with the school newspaper and it was amazing! I never expected that opportunity when I started college. The classes you take and what you learn change you for sure. Also, just the experience of going to college changes you for the better. People can have wonderful skills in one thing, but they aren't expanding those skills. That is what college does: expands your skills and makes you learn more. If you attend college, you aren't trapped doing one thing all of your life.

I will admit that I got both of my jobs from people who I knew. But I don't feel it was just because I knew them. I feel it was because they knew I was succeeding at attending college. Therefore, they knew I was intelligent. There is a big difference between having basic skills and having a diploma. The latter gives you a lot more opportunities in this

world.

I am not saying college is for everyone with a disability. First of all, you have to be determined and have a lot of patience. Classes are hard and you have to take your time. That is why I took only one or two classes a semester. I was a writing major and never could have taken more than two classes at a time. Second, you have to have time for assignments. On average, a ten-page paper took me at least 30 hours to write. You also need time to read assignments. You could have 150 pages to read in one week. When I took literature classes, I got books on tape when I could. Finally, college is expensive. Since I went part-time, I didn't qualify for loans. I was fortunate that I went to a small university and my parents could afford the tuition. I graduated from college debt-free.

While all these things are factors to going to college, you have to ask yourself if it is worth it to you. For me, attending college was a huge dream of mine and nothing was stopping me. There were times when I was in such severe pain, but I never gave up. The dream was greater than the pain. I also didn't care how long it took me. I was living my dream, and there was no time limit for me. I worked hard for 10 ½ years, and the greatest reward was going across that stage and receiving my diploma.

In conclusion, I hope I have helped you understand that attending college is possible for people with disabilities. It might be a struggle, but if you are determined enough, you can do it. I also hope I have helped you understand that college is an experience of a lifetime. Having a college degree changes your life. You are more respected and have more opportunities for better jobs. You will have more knowledge to have more skills. What is next for me? Graduate school! No, I am not stopping! I hope to start in January. I know it will be 100 times harder than regular college, but I am up for the challenge. I love learning, and I want to be the best writer possible. If it takes me another 10 ½ years, then so be it! I want to achieve another dream!

If we have time now, I will take questions. If not, I will be at the conference all day today and until lunch tomorrow. Please feel free to come and see me. Thank you for letting me speak to you today!

Employment: Social Capital Can Be Your Friend

Jeff Parker, B.S.
Chief Operations Officer
UCP/CLASS - United Cerebral Palsy of Pittsburgh
President, Three Rivers Community Foundation
Pittsburgh, Pennsylvania

The presentation will examine the impact of social capital on all aspects of our lives including health, happiness, housing, and with a special emphasis on employment. Particularly, we will look at the power of social capital for individuals not only during the job search, but also once hired. We will also look at how organizations like SHOUT can bolster employment opportunities for people with disabilities by building relationships and connections with businesses and organizations in the community. The presentation will leave the attendees with a practical and thorough understanding of the astonishing advantages of building social capital in their lives.

In the 60's and 70's programs began to bring people with disabilities out of isolated institutions and into the community. As part of these programs, extensive services were developed to support persons to live in their own homes or places of their choice. However, although these services provide an extensive array of supports for persons with disabilities to live in the community, they were not designed to integrate or include these persons into active participation in the community. For example sometimes these supports are provided through living in residences and frequenting community centers that are almost exclusively reserved for people with disabilities. This system keeps people in the community but does not make them members of the community.

Although over the years, public facilities and human services have become "accessible", the same kind of access to social capital, in other words the ability to build relationships in the community, has not been reached. This is because access to facilities and services can be done through the legal system which is really attuned to this concept now, while access to relationships is a very different concept. It's very clear to most members of the public that sidewalks should have curb cuts and buildings should have accessible entrances. Additionally, if you would stop any typical person on the street and ask him or her what you might do for a friend who uses a wheelchair, or an augmentative communication device, he or she will undoubtedly suggest a place to get funding, or to call United Way to find a place or program for this person. Their direction would be to seek out services, rehabilitation or the physical and environmental changes. In other words someone's first thought would be rehabilitation. It just does not naturally come to mind that an important need of a person would be to develop relationships and interaction with others, in other words become a member of the community.

Instead of rehabilitation, what is needed is an agenda that includes social capital which builds relationships on what we have in common, not our differences, and ultimately

builds a community where each of us belongs. This is community building rather than rehabilitation. Enormous evidence that has accrued over the past several decades demonstrates the significance of social capital – the wealth that people have in relationships – in building safe, healthy, prosperous, and democratic communities.

The central principle of social capital is that social networks, in other words relationships, have value. Social capital is a resource that individuals enjoy and obtain from being part of a community. Numerous studies have documented how communities with higher levels of social capital are likely to have higher educational achievement, better performing governmental institutions, faster economic growth, and less crime and violence. And the people living in these communities are likely to be happier, healthier (both physically and emotionally), and to have a longer life expectancy.

Most agencies serving people with disabilities in the United States and Canada, report that the individuals they serve have greater challenges in health, happiness/ satisfaction, longevity, vocational success, housing, and the like. In fact, what data that does exist in the disability community, confirms what most disability advocates know through experience. That is, national surveys report that people with disabilities have greater levels of unemployment, institutionalization, social disconnection, and lower levels of life satisfaction.

Social capital is a dynamic concept and it has an impact on the micro (individual or family), meso (community or organization) and/or macro (city, state, or nation) level. Research suggests that a community's aggregate social capital – social trust, norms of social reciprocity and participation in the community – can have a positive impact on the whole community, including those with less or limited social capital.

Just as the types of relationships that people have are different, so are the benefits and rewards associated with them. Sociologists describe three types of support that flow through one's social network: instrumental, emotional and informational. Instrumental support refers to the provision of tangible resources, such as a ride to the store, a place to stay or help with child care. This type of support is typically provided by those with whom one is closer and more intimate. Emotional support includes help coping with stress and other emotional needs, such as talking to a friend about a bad day, and is provided by individuals that one is close to and trusts. This type of support has been linked to improved health and happiness outcomes for all individuals. Lastly, informational support includes access to information and resources and can be provided by any member of one's network, whether a close friend, or someone barely known. All three types of supports are important, and the value of one's social capital is how these resources play out. It also starts to become clear how these supports are important and can be your "best friend" when looking for a job.

Social capital is clearly something to reckon with. The research, studies and reviews are overwhelmingly consistent in their conclusions that the more relationships people have – especially key, close relationships – the better they are able to deal with the stressors of

life and the better their lives and health become. The opportunity for employment is also one of those things that make our lives better.

Over the past 25 years, researchers have been looking closely at the effect of social capital on health and happiness. Study after study has concluded that the more social capital an individual has, the fewer sick days and sad days he or she experiences. Research has demonstrated the more social capital present, the greater the survival rate from heart attacks, less risk for cancer recurrence, less depression/anxiety and less severe cognitive decline with aging. Similar studies over the same timeframes found that social capital predicts who is resistant to illness. Going even further, the literature suggests that social isolation (the lack of social capital) actually causes disease.

Without a doubt, social capital is also an important factor when it comes to employment. The available research on employment suggests that between 40 and 70 percent of working people report finding employment opportunities from a friend, and often not a close friend. While close relationships have been tied to better health and other related outcomes, acquaintances or "weak ties" have been shown to be vital in finding employment opportunities. These weak ties often develop from people in one's own network, for example a friend of a friend. The literature suggests that these weak ties are especially useful for finding employment, because these people have additional contacts outside of one's own social network and, thus, access to a diverse amount of information, resources and possible job opportunities. With our presentation, we hope to offer encouragement to create these relationships.

Social capital can play a dual role in employment not only helping to find jobs but retain jobs as well and is an additional tool not always provided to job seekers. People with disabilities face many obstacles when it comes to employment. Vocational rehabilitation programs are designed to assist and guide people with disabilities to secure and maintain employment and to be a resource for employers who seek employees. There are three types of capital critical to the employment success of people with disabilities: human, cultural and social. Many vocational rehabilitation programs primarily focus on helping consumers to increase their human and cultural capital, that is to help them improve work related skills and to learn common office culture. Very few programs look at social capital as a key to employment, yet we are learning that social capital plays a critical role in helping individuals find and sustain employment. Finally in understanding the importance of promoting the development of social capital, organizations like SHOUT can see the importance of developing relationships and building bridges to the business community on behalf of their constituents.

All in all, as far as employment goes, social capital is your best friend because it can increase your opportunity to locate jobs, enhance your opportunity to retain your job and the power of social capital for agencies promoting and assisting their members with employment cannot be denied.

The Speaker Circuit as the Road To Employment

Chris Klein, M.Th., Executive Director
Clay Vessel Inc.
Holland, Michigan

Hi, how are we all doing? That is great! My name is Chris Klein, and I am a motivational speaker. I live in a van down by the river. I heard you want to be a writer. That is great. You are going to be a great writer. You are probably thinking that you are going to leave this place, and grab life by the throat, and make something out of your life. I am going to tell you that isn't going to happen. Life is going to grab you by the throat, kick you in your butt, and you are going to live in a van down by the river.

I'm not sure how many of you watch Saturday night live, but the late comedian, Chris Farley, did a routine about motivational speaking. . It was this routine that made fun of careers, jobs, and motivational speakers. I thought it was appropriate for me to begin this speech with a little Chris Farley.

We are here to focus on jobs. I know everybody here wants to be employed, and my topic is about how motivational speaking became my career. Before I talk about that, I need to have you understand that this wasn't in my plans. My dream wasn't to become a speaker. Actually, being a motivational speaker wasn't even a thought of mine.

As I thought about my topic, I realized that my journey in becoming a speaker has taught me a few valuable lessons. I want you to come along on this journey with me. I know not everybody can become a speaker, but I believe the lessons I have learned on this journey are valuable.

The first lesson is you have to have a dream. If you are going to do something with your life, you have to have a dream. I think this is a lesson that sometimes gets overlooked by a lot of people. The dream could be a dream that might not be achievable, but without a dream, you have nothing to go after. I believe having a dream makes you want to pursue a goal. Once you are pursuing a goal, anything can be achievable.

I grew up in a sports family, and from early on in my life I wanted to be involved in sports. As a child, I had a dream to be a football player. I was going to be a place kicker for the Chicago Bears. I would practice and practice because I did believe I was going to be a place kicker.

My family knew I was never going to be a place kicker, but they didn't discourage me. Instead, they made me believe I could do it, and while it wasn't possible, they wanted me to believe I could be anything that I wanted to be. This was a very important because as things developed later on in my life, I believed I could be successful.

Are you like me? Did you have a dream as a child? Were you able to dream about what you wanted was to be when you were growing up? I believe in dreaming to be something. It might be a far fetch dream, but if you are dreaming to be something, it is easier to block out all of the nay sayers. Whether you are dreaming to be an pilot, a fireman, or a ballerina, you are dreaming about doing something with your life. That is the the first step to having a successful career.

The dream of being an athlete led me to figure out ways that I could participate in sports. I quickly became interested in being a team Manager. However, keeping stats wasn't enough for me. I wanted to be able to play a sport. As I entered junior high, I was able to develop a wheelchair soccer league. It led me to develop other wheelchair sports programs.

After graduating high school, I felt like I found my career. I believed that I could develop many sports programs for people with disabilities. I decided to major in Kinesiology, and minor in business. After my third year in college, I visited Michigan state university. They had an adapted physical education master degree program. The plan was to enroll there to get my masters in adapted physical education. Then, I was going to develop a business that would develop sports programs for people with disabilities. This was a dream of mine because I wanted most people with disabilities to experience competition.

The second lesson is pursuing that dream. I know it might not be achievable, but if you don't pursue it, you are going to get complacent. You are going to be happy with the status quo. When that happens, life becomes less enjoyable. You see, when you give up on a dream, you give up on life. It is important to pursue your dream because you are putting yourself out there. You are developing your abilities and gifts along the way. You are showing people that you want to make something of yourself. People are going to respect you for going after something, and they are going to see your abilities.

I pursued my dream to the fullest, and as I was doing that I found that I had another gift. In the process of pursuing my dreams, I began doing presentations. This started early on in life. I would go to a school, and talk to the students about my life. It was fun to do, but I was so focused on doing what I wanted to do, being a speaker never crossed my mind. I started giving my testimony in churches and high school chapels, and I continued to do that through college. I knew people enjoyed my speaking. They were inspired by me, but I didn't think about making a career out of it.

In July, right before my senior year of college, I was approached by Marlin Vis, I didn't know Marlin personally, but I was attending the church he was the pastor of over that summer. He came up to me one Sunday morning, and asked me to preach a sermon with him on the Labor Day Sunday morning. I agreed, and I didn't think much about it.

Marlin and I only got together for a couple of times before that Sunday, so he allowed me to contribute my own thoughts to the passage that we were using. The last time we met,

he told me he believed I had a gift, and he was looking forward to Sunday. Sunday came, the sermon went very well, and people were really appreciative. I went back to college, and started my last year. On the Wednesday after Labor Day, there was a knock on my dorm room door. It was Marlin. He told me how he appreciated working with me on Sunday, and people had been calling him non-stop. As we talked, he really encouraged me to look into going into the ministry.

After that conversation, it was the first time my thought process began to waiver. Yes, I knew I would be an asset whichever direction I would choose, but I began to feel a calling for my life. I guess it was a feeling of a deeper sense of purpose. I thought about it long and hard. In the end, I decided that I had to pursue this deeper sense of purpose. I decided to enroll into Western Theological Seminary.

The final lesson I want to talk about is the willingness to make adjustments on the fly. I want you to have a dream. I want you to pursue and dream, yet we need to sometimes adjust on the fly. It is possible that as we are pursuing a dream, we might find some other gifts that we have. Those gifts could lead into a better sense of our purpose in life. We need to be open to adjust on the fly, and go after something that might not be our dream, but gives us joy just as much.

It wasn't that I was giving up on my dream, but this other thing gave me just as much enjoyment. I decided that I had gifts that might have been wasted if I didn't pursue the ministry at the time. All along, I believed somehow these two dreams would connect up in someway.

What I want you to take out of all this is that life is full of adjustments. I believe we all know this, but I know for myself sometimes I feel like I am always making adjustments. I believe living with a disability we have to adjust more, and speaking for myself, that gets old quickly. Yet, when it comes to a job, we have to remember we aren't alone in that boat. The job market is unpredictable for most people, so everybody is making adjustments.

Obviously, I didn't title my speech my life as a pastor, so you know I don't have my own church. After three years in seminary, the denomination that I am involved in couldn't see past my disability. On my final classis exams, the questions weren't really about my theology, but were more about how I thought I was going to pastor with a disability. I tried to answer their questions with a theological answer, but somehow they said I was being defensive, so they didn't approve my certificate of ministry.

I had to make another adjustment. I was frustrated, depressed, and their decision really zapped my spirit. I was depressed for about a month or two, and really had no motivation to do anything. This was really frustrating to me because I don't get depressed. For those of you that know me, you know I always like to be on the go and doing something. For me to sit around and want to do nothing was strange. My family and friends were worried about me, but after about two months, I began to see a bigger vision for my life.

I began talking with my friends about a ministry where I could speak and write, sharing

my story with people who need to hear it. They began to get behind the idea and really encouraged me. The more I talked, the more my spirit became alive. In fact, my spirit, was jumping up and down! I had joy and drive and purpose in my life again. I wouldn't have dreamed I would be a speaker. I couldn't talk, so why would I want to be a speaker. Yet, sometimes you have to think outside of the box. I had a gift, and I needed to use that gift. This is what God had been preparing me for all along, and I was eager to get started.

For the first five years of this new adventure, I focused in on speaking at churches, camps, Christian middle and high schools, and Christian colleges. This was where my training was at, and I felt that I had a very unique way of speaking. I was able to speak at a couple of big conferences within the first couple years, which opened the door for me to write a couple of articles for a couple of Christian magazines.

This led me to begin writing a book. I am currently writing a book called *Lessons from the Big Toe.* A book that will take people on a life's journey, which I have been taught many lessons. The biggest lesson I have been taught is we are all in this together.

After five years of speaking, I felt like I could do more with the platform I had. I started researching different organizations to see what was missing. I wanted to make sure I was going to fill a void, and I didn't want to do something another organization was already doing.

After a lot of talking, dreaming, planning, trying, praying, and learning, a new ministry—Clay Vessel, Inc.—was born. I believe we are all unique vessels. We all have unique gifts inside of us, and I want to help people discover the gift they have inside of them. My dream is to help AAC users become everything that they can become. This is why I am now traveling to different universities giving seminars on communication. I believe we have too low of expectations for people that have communication disabilities. I want to change that perception, and it starts by educating families, teachers, and yes even speech language pathologist about what communication is all about.

Clay Vessel wants to change the world. I love speaking, but my dream as a high school senior was to help people play sports. It has changed somewhat, but my dream is to still help people. I want to help people that use AAC see that anything is possible. I want people that use AAC to believe they can be anything they want to be. When a communication disability hits, many people believe life has to stop. We know that life doesn't have to stop.

While speaking has become my career, I wouldn't be Chris Klein if I stopped there. I believe I can do more, and that is why I am working on starting a mentor program. I believe we can pair up successful AAC users with families, children, and even older adults that are just starting out on an AAC device. This would give people the opportunity to see and experience a thing of an AAC user. We wouldn't only mentor people, but we would be able to mentor schools, businesses, churches, and etc. This would not only educate people that are starting out on an AAC device, but also the places that would encounter a person with AAC.

I understand everybody here wants to have a career. Everybody here wants to be able to support themselves, and their family. Yet, do you believe you can change the world? Do you believe you can make a difference in somebody's life? Are you willing to join me in trying?

Developing and Supporting Leadership Among People Who Use AAC

Faye Warren, B.A., Chair, PWUAAC (People who Use AAC)
ISAAC Board
Ocoee, Florida

Sarah Lever, A.A.
Avon Representative
Charlotte, North Carolina

As an Executive Board member for ISSAC, I am the Chair of the PWUAAC, or People Who Use Augmentative Alternative Communication. When I was first appointed to this position, I had to ask what PWUAAC meant. Did it mean Powerful Women Using AAC? No, that couldn't be right because ISAAC is gender inclusive. Could it mean Parachuting over Wyoming while Using AAC? That's far out there. I finally resorted to asking Gail Van Tatenhove what it meant.

Besides attending executive board meetings on Skype, conference calls or in person and actively helping with ISAAC conferences, my main area of responsibility is the continuation of the LEAD project. Here we go again. Another acronym: Leadership Education and Awareness Development. LEAD proposes to help train them for leadership roles. Families and anyone interested in knowing more about meeting the language and communication needs of those with these challenges can go to the ISAAC website as a resource and to LEAD in particular. My friend and past Chair of LEAD, Sarah Lever, and her committee, have already done several years of work writing LEAD objects. Myself, Sarah, Diane Bryen and other committee members are now editing these documents and adding to them as needed. Future LEAD modules posted on the ISAAC website and sent worldwide as e-news hope to address various ways of encouraging and training AAC users to become future leaders in their own lives and communities. ISAAC uses their website, with components like LEAD, to be a central place worldwide that users and professionals can go to for information and training regarding many areas of AAC including leadership.

Last November, Sarah, Diane and I had a meeting that focused on Leadership Development. I wrote a first draft called, Facilitating Skill Training for Leadership in AAC. Though still in process as other committee members continue to give input, I'd like to share some of our training ideas. They are common to all AAC users who have already traveled the road to employment and leadership roles.

People who use AAC that are interested in leadership roles can develop leadership skills by a variety of proactive and supported life choices. Some of these include an AAC user becoming literate and proficient in the use of their AAC device; having Internet Access;

developing the ability to direct others in personal care needs and receiving appropriate academic assistance in school. Utilizing high school leadership opportunities such as, student council; clubs; classes in public speaking or drama; volunteering to work afterschool for community organizations or churches, all develop leadership skills. Mentoring younger students who use AAC through donating time to go into elementary schools to tell about our lives, or just to communicate with them one on one, is leadership. Becoming a conference speaker or presenter for a local, national or international organization that promotes AAC encourages other AAC users to raise the bar higher in their personal goals and dare to become leaders.

Lastly, another of my responsibilities as Chair of PWUAAÇ is to promote AAC Awareness Month each October. This year, we would like AAC groups worldwide to hold events that raise AAC Awareness and are fundraisers for the benefit of their own communities. A new idea for this year is to hold relays called "The Power of Communication," at school, community or church sites. For more information about AAC Awareness Month, please go to the ISAAC website or contact me. Become a part of the worldwide AAC movement to educate others about AAC and develop future leaders who use AAC.

Developing and Supporting Leadership Among People Who Use AAC (cont.)

Faye Warren, B.A., Chair, PWUAAC (People who Use AAC)
ISAAC Board
Ocoee, Florida

Sarah Lever, A.A.
Avon Representative
Charlotte, North Carolina

LEAD Role Play PRESENTATION

Faye:
(Introduction): Sarah and I will role-play an exchange, which will describe the LEAD Project within ISAAC, the International Society of Augmentative Alternative Communication. Sarah is the past ISAAC Chair for People Who Use AAC. I am the present Chair.

(Sarah and Faye roll into the room toward each other)

Sarah:
What is up, girl? How is it going?

Faye:
Sometimes, I don't feel like I am making a difference in the lives of other AAC users, except when I go to my job mentoring my students in my school district. That is the bomb! Yet, other then that, I have felt like I reach only a few AAC users on the local level. What is up with that? I mean, Sara, how can I make a difference to people who use communication devices throughout the world and also raise AAC awareness?

Sarah:
The International Society for Augmentative and Alternative Communication has been working on a project for leadership. It is called LEAD. 11 years ago ISAAC set up in its Bylaws many opportunities for leadership for members who use augmentative communication. (Some of the opportunities include: board membership, committee membership, committee chairmanship, or Executive Board membership). The objective was for the person in the role to lead by public example, therefore demonstrating that it is possible for people who cannot speak with their natural voices to be in significant and influential roles. Most importantly this was to be demonstrated at the very top of the Society. The Leadership Chair activities were very successful in breaking down attitudinal barriers and in giving many non-speaking people new perspectives on their lives.

In particular it noticeably increased participation by AAC users in the Society's activities, nationally and internationally, in conferences, workshops and research projects. The success of the Leadership Chair has, however, also highlighted a need that must be addressed and that could only have become apparent as a result of these positive developments. We need more people who use AAC in leadership roles in ISAAC.

A Person who uses AAC has the right to have an attendant attend the meetings. The attendant can have access to any materials privy to the member, and assist that member in reading/reviewing the materials. The attendant may also communicate on behalf of the member if so requested by the member.
Accessibility is another important aspect of getting AAC users on committees or boards. Accessibility is anything between the building that the meeting is being held to how people get the documents. I am going to give all of you some tips of what is accessible is in the world.

In most of the countries of the world the buildings have to be wheelchair accessible. All the public buildings have to be wheelchair accessible. Buildings must have a wheelchair accessible way in. This includes a ramp or an elevator if there are stairs to the door or room. Doors that open wide enough to accommodate a wheelchair, the room has to be well lit. The bathrooms have to be accessible, i.e. grab bars, higher toilet and sink.

Faye:
Thank you, Sarah. A question: Does LEAD offer training in leadership or mentoring?

Sarah:
Yes. In further developing the LEAD project my committee began, you and your LEAD committee are developing strategies that AAC users can utilize to increase their leadership skills. We are communicating these through the ISAAC website, emails and e-newsletters to ISAAC chapter members. There are three levels at which people who use AAC can choose to develop leadership skills. Not everyone will want to do all three. The first level is in their personal lives. An important example of this is being able to use one's AAC device to direct personal care needs. This is the first step to independence and taking the lead in one's life. The second level is developing social skills. These include making arrangements for transportation in order to meet up with friends or a common interest group. Developing friendships or dating by becoming proficient at using one's AAC device is necessary. Taking the lead in one's own social life means activities like attending entertainment venues or traveling to new places with friends. The third level of developing leadership skills is for AAC users to become active in their communities, locally first, then perhaps even nationally or internationally. One can begin this process by joining an organization, church, or volunteering with an organization that helps others in need. Mentoring is an area we need to explore more. Hey, Faye would you tell me about your mentoring experiences?

Faye:
I realized my interest in mentoring others while in high school. I went to a children's head start program to tell them stories on my AAC device. I also went to nursing homes to tell jokes to the elderly residents. Good or bad jokes, at least they laughed at them!

Just over two years ago, I volunteered to mentor and tutor students who use AAC in my local school district. After about six months, this led to a fifteen-month grant from PRC to continue this work as a paid professional. This coming September, the Orange County Public Schools in Orlando, Florida, will pay me themselves to continue to do this job. As part of the LEAD project, I recommend mentoring, either as a volunteer or professional, as one of the best ways to become a leader.

As an example of how an AAC user can mentor and impact the life of another AAC user, let me tell you about Michael. He is a young man I mentor in School who lives in a group home with people who are mentally challenged. He is intellectually intact. Outside of my work hours, my attendant and I pick him up and go to the mall, movies and the science center. To see the joy on his face is priceless. I have been socializing with him to get him used to the outside world and to communicate with people on his communication device. Though he would not communicate with anyone before, he absolutely loves going out and using his device now. It only takes one person to change someone's life and open his or her eyes to new possibilities. I also mentor a young girl who is twelve years old and lives in Hong Kong. Through Skype, using our Eco devices every Friday late at night, which is my time zone, and Saturday morning for them, we communicate with my introducing her to new vocabulary words each time. At first, the young girl would not look at her Eco, acting as if it was a demon, because she was so used to using her word board. I asked her if she would not rather use her Eco AAC device to communicate on her own instead of using her father for her mouthpiece. Besides, I told her that she could not be flippant to her father while he was in control. Not good. She laughed, but she started using her Eco.

May I also suggest that AAC users have a wireless cell phone connected their communication devices. This will greatly impact independence and leadership ability. I use my cell phone to direct my personal care attendants, make social arrangements and for business purposes. I also connected my Eco cell phone to Facebook where everybody can talk to me on the go. Friends or anyone can reach me with questions about ISAAC or LEAD. I love texting people. I can communicate worldwide by using Clear, a wireless network that runs off of cell phone towers and interfaces with my Eco2 phone application, which includes an internal blue tooth.

In conclusion, I hope to see more and more of the older AAC users mentor and train younger people who use AAC. The result would be a better understanding of the importance of using AAC. LEAD is on Facebook under ISAAC LEAD Support Group. If you have any questions, please come and see Sarah and I after this session or e-mail Sarah at sarahlever@carolina.rr.com and me at warrenfaye@yahoo.com. Make plans now to attend ISAAC 2012 Pittsburgh. Thank you.

Twenty Years of Full Time Employment: A Lifetime of AAC

Richard D. Creech, M.S.
Educational Consultant
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When I was growing up in rural North Carolina, no one expected me to grow up and actually to support myself financially <silence msec="100"/> as an adult. They could not comprehend how that could happen. They were looking at the realities of my situation. This was before any communication aids, before powered wheelchairs with head controls, before personal computers, before cell phones, and before the Internet. The problem with planning on today's realities is that the future is an undiscoverable country. Today's realities are not tomorrow's realities. Well meaning people, even my wonderful parents, planned on taking care of me until I died, or they died. That was their reality; however, I found that reality <silence msec="100"/> unacceptable. So, I asked God to change reality, and, man, did he ever!

As a child growing into an adult, I understood that work was necessary <silence msec="100"/> if I were going to have the independent life that I wanted. I loved my parents dearly, and owe everything to how they loved, taught, and raised me,<silence msec="500"/>, however, I did not want to grow old with them, knowing that they would eventually die, and I would be left alone, without any experience living alone. That would have been a nightmare. This is not my youngest son, feeling <silences msec="500"/>, he has informed my wife and I that he is no fool,<silence msec="350"/>, he is going to live with us for as long as possible, where he has low rent, no bills, free cable, free laundry, and the whole downstairs to himself, and home cooked meals, a couple times a week. In today's economy, I am at a lost to argue against his logic. But his situation is different from what mine was. First, he has a job,<silence msec="350"/>, so, he could make it without us,<silence msec="350"/>, and second, he is not totally dependent on us, as I was on my parents.

A child with disabilities has to have realistic dreams. I would have loved to have been an FBI agent or an emergency aid worker, but with my physical disabilities, which I knew were not going away, I knew those careers were not feasible. In 20 years, who knows,<silence msec="350"/>, we might have androids that we can jump into. But in 20 years, I will be 77,<silence msec="350"/>, I think I will be leaving the jumping for the youngins. I know this sounds like science fiction, but 20 years ago, so did Star Trek's communicaters,<silence msec="350"/>, now they are just old style cell phones,<silence msec="350"/>, they did not even have streaming video! I believe that humans have the ability to create anything that we can imagine. Not immediately, but once imagined, it is on the way to existing.

Even when I was a child, I knew working at Walmart was not going to cut it. No offence to Walmart, but if I were to have the life I wanted, I would need expensive equipment,<silence msec="350"/>, nice place to live, and if I wanted to marry,<silence msec="350"/>, well, wives are very, very <silence msec="100"/> expensive,<silence msec="500"/>, extremely, unbelievably <silence msec="100"/> expensive. And if my wife is in the audience, I would be wise to shut up on that subject. Everyone needs to plan for a career that will secure the income to live the life the person will desire.

Unfortunately most of our kids are too busy living in the moment <silence msec="100"/> to plan that far ahead. I did not have that problem,<silence msec="350"/>, my childhood was mostly boredom,<silence msec="500"/>, I had plenty of time to think and to plan. One of the things that I concluded was that I would have to build a career from my uniqueness. Instead of seeing my disabilities as disadvantages, I would have to turn them into advantages,<silence msec="350"/>, present them as unique <silence msec="100"/> knowledge and skill areas <silence msec="100"/> that other people do not have. This has been my mind set since childhood.

Since age 27, I have had several jobs. My first was as a spokes person for the Phonic Ear Company <silence msec="100"/> demonstrating the HandiVoice 120. Remember, I used my unique abilities in getting the job. Phonic Ear paid me to go <silence msec="100"/> to conferences and symposiums <silence msec="100"/> to demonstrate the HandiVoice 120. This device was so new, and shall we say, non user friendly <silence msec="100"/> that the professional community could not believe that anyone would be able to communicate with it. Phonic Ear needed someone who could communicate <silence msec="100"/> with the Handivoice, and I presented myself as an augmented communicator who could communicate with the Handivoice. During this time, I was also getting paid by churches and community groups to speak to them on my <silence msec="100"/> unique, yes, there is that word again,<silence msec="250"/>, to speak to them on my unique perspective on life, and God. The money was not great, but great training in public speaking.

Then I got a call from a guy <silence msec="100"/> named, Bruce Baker. That was <silence msec="100"/> one of The great pivotal points <silence msec="100"/> in my life. My family and I invited Bruce down to our home. Bruce came; we talked. After Bruce left, my Dad, said something like that man has brilliant ideas, but he will not be able to stay on them long enough to see them through. I replied something like, I think he will,<silence msec="250"/>, if he is medicated.

My friend, Bruce Baker, did develop Minspeak, with or without medication, I do not know. A brilliant idea from a genius. I helped Bruce to sell his idea to Barry Romich,<silence msec="350"/>, and I went to the Prentke Romich Company to demonstrate the first prototype <silence msec="100"/> of the first Minspeak 1. I felt like neal arm strong! Only, Neal had more training before they sent him up,<silence msec="500"/>, I was given the Minspeak 1, and asked to use it, in front of cameras. No pressure, folks,<silence msec="250"/>, just the usual make it, or break it, moment. That was how I became Prentke Romich Company's spokes person.

During this time, I had another job as a security guard at Wesleyan college <silence msec="100"/> in Rocky Mount, North Carolina. I am not sure what unique <silence msec="100"/> knowledge or skills got me that job, except to say I was the only security guard who had a powered wheelchair, who could ride <silence msec="100"/> all over campus at nights looking for broken lights,<silence msec="350"/>, the other guards would have had to walk. Then, as a part my master's program I <silence msec="100"/> Interned at an assistive technology center at a mental health hospital,<silence msec="500"/>, interesting to say the least. After I graduated from my Bachelor's, I became the Editor and Chief of Minspeak's first newsletter, not the one you have now,<silence msec="350"/>, the one you have now is much better. That was back when you actually used real paper and ink and real stamps to mail newsletters the old fashion way. The concept of me being editor of anything <silence msec="100"/> still blows my mind, because as my Mom would tell you, I cannot spell worth a lick.

Having a job is wonderful, but having a career is much better. The difference between the two <silence msec="100"/> is a job <silence msec="100"/> you do to live,<silence msec="350"/>, a career <silence msec="100"/> you do 25, 30, 35 years, and look back on those years, I hope, and say, wow, I did that and it was special,<silence msec="500"/>, even if it was just keeping your family safe, fed, and happy. These days That is very special.

Having a career requires an education higher <silence msec="100"/> than high school, unless you have a very extra ordinary talent <silence msec="100"/> or a winning power ball ticket. Even then you better get a higher education, else someone is going to come along and steal your money. When I was young, there was no Power Ball in North Carolina,<silence msec="500"/>, and I tried painting with my headpointer,<silence msec="250"/>, zero talent. So, I opted, to go the education route. Started at Wesleyan, Rocky Mount,<silence msec="350"/>, transferred to East Carolina University, where I got my Bachelor's in English non-fiction writing. I know, a person who is lousy at spelling getting a English writing degree, go figure. But I can tell you where to put your commas and semi-colons! I got my master's at East Carolina in Speech Pathology, Communication Sciences tract. I know, a person who cannot speak orally <silence msec="100"/> getting a master's in Speech Pathology,<silence msec="350"/>, another go figure, moment. However, I did love the communication sciences tract,<silence msec="250"/>, and I would like to say that all the stuff the professors taught me, really helped me in my work. It did not. However, it was learning to work all day and all night <silence msec="100"/> if necessary <silence msec="100"/> on something I did not <silence msec="100"/> understand until I understood,<silence msec="350"/>, it was not missing a class no matter, rain, snow, heat, cold,<silence msec="500"/>, it was learning to work with other students and the professors some of whom were absolutely crazy,<silence msec="500"/>, and it was learning to set priorities that really prepared me <silence msec="100"/> for the job and career <silence msec="100"/> I have now.

After finishing my master's, thinking that I had a position at the Pennsylvania Assistive Technology Center, I moved to Harrisburg. As it turned out, I had jumped the gun by a

little more than a year. By the time I had settled in Harrisburg, the Pennsylvania assistive technology center had a new director who did not know <silence msec="100"/> that I had been promised a position. I made an appointment with the new director, Fran Warkomski. I explained the situation and my qualifications. Fran told me that she did not have money in the budget that year for a new position, but next year she would put a new position in the budget for an Educational Consultant with qualifications that would match mine. Fran's word was golden. But I still had over a year to wait,<silence msec="350"/>, so, I did some networking and got hired part time by Pennsylvania Initiative on Assistive Technology, PIAT, based in Temple University, to start a Short Term Loan program to adults. Interestingly, piat had contracted with the Pennsylvania assistive technology center for space, and set a side <silence msec="100"/> $100,000 to buy assistive technology equipment to loan to adults. However, Pennsylvania assistive technology center could not do anything, because their mandate is to serve children pre school through high school,<silence msec="500"/>, therefore, although Pennsylvania assistive technology center <silence msec="100"/> could rent the space, they could not assist PIAT in setting up an adult assistive technology loan program. So, PIAT, hired and gave me a hundred thousand to purchase assistive technology for a loan program for adults. At the time, 17 years ago, a hundred thousand bought more than it will today, but not that much more. PIAT hired me part time,<silence msec="350"/>, so, I needed a second job. So, at a Pittsburgh Employment Conference, I found the director of the office vocational rehabilitation sitting at his table,<silence msec="350"/>, introduced myself,<silence msec="350"/>, told him that I needed a job,<silence msec="350"/>, and that his vocational rehabilitation counselors did not know much about assistive technology,<silence msec="350"/>, and I could teach them. He told me to call his secretary Monday morning to set up an appointment. My wife was so embarrassed. I told her, hey, this is an employment conference, and he is the director of the office of vocational rehabilitation. What better time to talk to him. That Monday I did call,<silence msec="250"/>, got an appointment. He gave me a year contract through the Pennsylvania assistive technology center to do <silence msec="100"/> regional trainings of vocational rehabilitation counselors on assistive technology through out Pennsylvania. So, as I was waiting a year and a half for the Pennsylvania assistive technology center to hire me full time, I was there eight hours a day under two contracts with two different organizations. Fran could not forget about me, even if she had wanted to!

After my other contracts were completed, Fran did hire me full time at Pennsylvania assistive technology center, slash, CISC, slash, PaTTAN, Pennsylvania Training and Technical Assistance Network,<silence msec="350"/>, as an Educational Consultant in secondary transition. My first big project was to design a survey <silence msec="100"/> of students transitioning from school <silence msec="100"/> asking if the assistive technology they use help, and were they taking the assistive technology <silence msec="100"/> with them after school, and did they feel they had the assistive technology they needed for life after school. Now, Pennsylvania does pre and post transition surveys <silence msec="100"/> professional designed and administered <silence msec="100"/> by an outside company, but mine was the first in Pennsylvania. I will be the first to admit that I did not know how to design and administer a survey. I was told to do one,<silence msec="250"/>, so I did. I would like to think that my survey and working with other

transition consultants helped to inspired Pennsylvania to develop continuing and professionally designed pre and post transition surveys.

My next big project was PaTTAN's first website. PaTTAN had decided to design one in house, and Jim Binkley and I were drafted to build and manage it. Jim knew about networking computers, and I, I was supposed to know about website designing. I guess that was because I was <silence msec="100"/> the Educational Consultant <silence msec="100"/> who knew the most about the Internet. We succeeded in building PaTTAN's first and second website. I only crashed it twice, well, maybe three times when I tried to get too fancy. I managed the website for around three years, until PaTTAN finally decided to hire a professional company to design a professional website, thanks God. After that, my main job on the website was managing the online resources, training brochures and training handouts, and to make sure that all were posted in accessible formats.

For the past two years, I have been mainly redesigning PaTTAN's Short Term Loan program. Some of The kits were obsolete. Some of even <silence msec="100"/> the newer kits had been Discontinued by manufacturers, and it makes no sense to loan them <silence msec="100"/> if people cannot purchase the device, unless of course, that device was similar enough to another device <silence msec="100"/> that a student could be evaluated on the discontinued device <silence msec="100"/> for a device still on the market. I have been having to make that judgement, and then get permission to pull a device from the STL if I think it should go. That is not easy, folks.

PaTTAN has a new website by a new design and management company. Karen Narvol and I designed the STL section. So, everything you like, we did,<silence msec="500"/>, and everything you don't like, that is because Frameweld did not follow our instructions! Imagine our distress when we learned after the launch of the new website, that our STL database could not handle <silence msec="100"/> the way Frameweld would be exporting STL orders <silence msec="100"/> to us. So, I was assigned to re-design the STL database <silence msec="100"/> while it was still being used. I still don't know how I got that assignment. I had not designed a Filemaker database in 12 years,<silence msec="350"/>, that was before Filemaker was relational. The STL Filemaker database was created 20 years ago by an amateur <silence msec="100"/> like I am, and it was a royal mess. Over the years, fields had been added when needed, and placed wherever. And the worst,<silence msec="250"/>, the Requests Database was a completely separate database. Someone had to open the Requests Database,<silence msec="350"/>, find an un-filled request,<silence msec="350"/>, open the STL Database,<silence msec="350"/>, see if the requested kit was available,<silence msec="350"/>, if so, the person would copy and paste information from the Requests Database <silence msec="100"/> to the STL Database, so that the kit <silence msec="100"/> could be shipped. Absolutely ridiculous, as judge Judy would say. For the last <silence msec="100"/> two and a half months, seven days a week, I have been learning how to fix a relational database, and designing and modifying the STL Database,<silence msec="350"/>, while all the time, trying not to crash the darn thing and bring the STL Program to a halt. The head of the tech department has threatened <silence

msec=”100”/> after I finished the STL Database, to give me the Accessible Instructional Materials Database to fix,<silence msec=”500”/>, I hope, he was kidding!

What’s next, who knows. The leed <silence msec=”100”/> assistive technology Educational Consultant <silence msec=”100”/> at PaTTAN Harrisburg <silence msec=”100”/> will be retiring soon, and someone has to keep an eye on the STL Program, and PaTTAN definitely is not hiring now. I am still checking everything posted on the website for accessibility. Although all Educational Consultants will be able to post their materials on PaTTAN’s website, some will take a long time to get comfortable doing that,<silence msec=”350”/>, I will continue doing some postings for awhile. I also have to start doing short, five minute, videos on augmented communication. In other words, I am going to stay busy.

If you are lucky, your job keeps shifting, forcing you to learn new things <silence msec=”100”/> and develop new ideas. I can think of nothing more boring than being at a job that does not change, that does not pre-sent new problems to solve for 30 years,<silence msec=”350”/>, except maybe, watching TV <silence msec=”100”/> reality shows eight hours a day.

Thank you for your time.

Long-Term Employment in a Project Benefiting People with Speech Difficulties: How Speech-to-Speech Can Facilitate Telephone Conversation for AAC Users

Bob Segalman, Ph.D., Sc.D. (*Hons. causa*)
Founder of Speech-to-Speech
President, Speech Communications Assistance by Telephone, Inc.
Sacramento, California

This talk will last only 5 minutes so there will be ample time for your ideas and questions. Please don't be shy. The FCC and I want to know your ideas.

Bruce asked me to talk about my work at the California Department of Rehabilitation and the telephone assistance service that came out of that work. What follows is a proposal for the next phase of the work that I did for the Department. The FCC has asked me to gather consumer ideas on a proposed new service. They want the service to be useful to AAC users and other people with speech disabilities. This service will include a video component to enable the operator to see the screen of the user's AAC device and/or the user's face. The FCC understands the serious problems with the current Speech–to-Speech, and they want to involve consumers in the initial design of the new service. It will be called Video Assisted Speech–to-Speech, known as VASTS.

I will describe the current design and ask you to tell me how to improve it to make it most useful to AAC users. To make a telephone call, users of VASTS would use a broadband connection and would install a camera and microphone on their PC. They would then call an operator on a website who was trained to help AAC device users be understood on the phone. This "VASTS operator" would relay the call between the AAC device user or other people with a speech disability and the called party. During these calls, the VASTS operator would watch the AAC device and the face of the caller with a speech disability, listen to any voicing and/or any electronic voice output. This operator would observe any gesturing or facial expressions made by the person with a speech disability, and use this combination of information to relay the content of the phone call to the recipient of the call. Additionally, AAC users may connect their device to their computer that is linking to the relay center. That will make it easier to transmit prepared or augmentative text to the VASTS operator. That is how VASTS works.

I'll be here for the rest of the conference, if you think of questions later. You can also ask Dr. B J Gallagher who is very knowledgeable about the topic and is here today. Dr. Gallagher, will you please stand? Okay, thank you and now for your questions.

Questions that the audience might want to ask:

1. How is VASTS different from Skype?

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2. Many people with speech disabilities cannot afford a computer. Will they be able to use Video Assisted Speech-to-Speech?

3. Who pays for the service?

4. How do you know that the operators will be adequately trained to work with AAC users?

5. Who will teach AAC users how to use Video Assisted Speech-to-Speech?

Demonstration of Text to Speech Call between Bob Segalman and Tim Geithner

This is Bob Segalman, here to demonstrate a video assisted Speech-to-Speech call. In this call you will see AAC user , the operator and the person being called when they each speak . Normally , only the AAC user and the operator would see each other. They need to see each other because they give both use gestures in order to communicate without interrupting the flow of the call.
I go to the STS provider's website and put in the number I want called. You will see me making a hypothetical call to Tim Geithner. He may resign as Obama's Secretary of the Treasury because of the deficit.
(Woman 's voice) Hello, this is Speech-to-Speech Operator # 1929. Number please.
(Bob) would you please dial 202-666-6630? That is , no money and ask for Tim Geithner.
(Woman 's voice) Dialing now.
(Another Woman 's voice) This is the office of the Secretary of the Treasury.
(first woman's voice) May I please speak with Mr. Geithner, Bob Segalman is calling.
(Second Woman 's voice) Just a moment please.
(Man's voice) Hello, this is Tim.
(first woman's voice) This is a speech-to-speech call. Your caller has a speech disability and will be using a voice output computer. Please wait for the go ahead and say go ahead when you are done speaking. Your call will begin now.
(Bob's Voice) Hi Tim, thank you for interviewing for my personal assistant position. Go ahead.
(Man's voice) Hi Bob, glad to talk with you again. Did I get the job? Go ahead).
(Bob's voice) No, I am sorry, Tim, but I was worried that you would not be able to hold my head above water while I swim on my back, go ahead.
(Tim interrupts) Surely I can do that .
(First woman's voice) Please wait for the go ahead.
(Tim's voice) Oh I am sorry.
(Bob's voice) Well, because you couldn't hold Obama's head above water with the budget, I had to give the job to Bill Clinton go ahead.
(Tim's Voice): But Bob, doesn't Bill have a substance abuse history? Go ahead).
(Bob's voice) I talked to Bill about that. It turns out that he never inhaled. Go ahead.
(Tim's voice) I did not understand what you just said.
(First woman's voice) I talked to Bill about that. It turns out that he never inhaled. Go ahead.
(Tim's Voice) Thank you operator. Are you sure that he never inhaled ? Go ahead.

(Bob's voice) I am going by what Monica Lewinski told me. Go ahead.
(Tim's voice) I didn't get that. Go ahead
(First woman's voice) I am going by what Monica Lewinski told me. Go ahead.
(Tim's voice) Well Monica is a reputable source. OK, thanks Bob. I hope that you will consider me for your next vacancy. Go ahead.
(Bob's voice) I sure will. Bye bye Tim. Go ahead.
(Tim's voice) Goodbye, Bob and thank you. Go ahead.
(Woman's voice) This is Operator # 1929 ending the call. Goodbye Doctor.

Situations and Strategies in Higher Education
&
Greetings From the President of USSAAC

India Ochs, Esq.
Attorney and Social Justice Advocate
President, USSAAC
Annapolis, Maryland

Bottom line - Whoever we are, wherever we come from, we all are placed into situations that require decision-making every minute of every day. What many do not realize is that many times it is the small things we may do today that can a difference in where we are years later.

I will be honest with the fact that I cannot share the kind of stories that were suggested to me when asked to speak about different situations while in school. Were there instances where others might have kept me from doing something I wanted? Of course, but for the most part it had nothing to do with my disability. Yet, as I was thinking about an incident my first year in college, everything clicked in terms of the message for this talk. In my second semester at college, a professor questioned whether I should be in her Environmental Law course – not because of my disability but because freshmen was not allowed to take the course. I had already been ready for that attack and used the fact that, even though it was still my first year in college, technically I was no longer a freshmen since I had enough credits to qualify as a sophomore after my first semester. Luckily I did not have to battle too hard on that front because another classmate had described my recent activity in contesting the student government elections that year, which made the professor more confident in my knowledge and skill set. And so, as I thought about how satisfying it was to prove the professor wrong in her initial impression of a "freshmen" sneaking into her class when I got an "A" at the end of the semester, I also realized that my education had nothing to do with getting hired. Instead, just as with my activity in student government getting me a pass to be in the Environmental Law course, it was little things that I did outside of the classroom that separated my employment applications from the rest, and in the end got me hired.

If you look at my resume, you will see that I doubled major in undergrad, got a masters degree and then went to law school. Yet, that does not mean I was a so called "career student". I always have believed that you will get a quality education no matter what the name of the college might be and so it was about what would be of interest outside the classroom that made the difference in the schools I attended. (I admit, the decision to attend UNC-Greensboro was made the moment I saw the 9 hole golf course on campus.) And so I jumped into everything that I was interested in – whether it was student government, writing for the school newspaper, playing soccer, joining a honor fraternity, or volunteering to be a court appointed advocate for kids in foster care. Part of my motivation was just my passion for so many different things in life, while at the same

time, I knew that these activities were all ways to network, build on my experience, and simply have constant interaction with people. Many of those skills and interests eventually landed somewhere on my resume, and made more of a difference than I ever expected.

We all should go into interviews with the knowledge that we deserve the job – after all, if you get an interview somewhere, that means they think you are among the best qualified for the job. Yet what separates your application from the others that may have made the final list? It's all about connecting with the person(s) in the interview and many times it's the little things that make that connection. Sometimes it's the name of the school you went to. Or sometimes, as occurred when I was hired at the RFK Center for Human Rights, it was the fact that I played soccer that motivated the director to offer me a position. There has not been a single interview where an employer did not take a moment to ask about at least one of my interests – and those are the moments where I am always able to show the employer who I am, and why they should hire me. While I focus on extra-curricular activities, I will say that sometimes it's the "fun" courses that make a difference too. Instead of taking corporate or tax law, I elected to teach a high school law class and take horseback riding my final year of law school. And to me, there is no better way to learn than if you teach - and it made a huge difference in interviews when I talk about my public speaking and communication skills.

Finally, to transition to my other role as USSAAC president, I will share that law school and my first job is what opened the path to USSAAC and the AAC Community. If it wasn't for a simple profile by Words+ after I graduated from law school and volunteered a year of service with AmeriCorps, I would never have been tracked down by my old SLP from the 1970s and invited to a conference in 2005 – and the rest is history. History which I am enjoying to help write as we move AAC forward within the United States.

Employment and Communication Performance

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Abstract
Surveys on job skills frequently list specific oral and written communication skills as being an essential requirement for employment. Therefore, employees can expect annual job reviews to include evaluation of their communication performance. Yet, most AAC speakers seeking employment have not had their AAC communication performance evaluated, and consequently do not have a long-term personal record to support: 1) meeting job requirements; 2) making decisions about upgrading to a newer AAC system; 3) identifying effects of aging on performance to make adjustments for possible decreases in performance. In fact, the experience of most AAC speakers is that their AAC professional team has never used critical performance data in making comparisons among possible AAC systems being considered and did not use performance data during treatment to optimize communication.

The goal of AAC is the most effective communication possible and is the expectation of professional and advocacy organizations, families and AAC speakers. The ability to carry on an interactive conversation in real time is one standard used to judge communication effectiveness. However, meeting the oral and written communication skills required by employers requires communication performance beyond social communication/networking or chatting at the water cooler. In addition, judging communication performance requires more than impressions of effectiveness. In order to have confidence that AAC communication performance has been optimized an AAC speaker must be informed of specific performance data achieved using the current AAC system. Such measures include, but are not limited to, average and peak communication rates, selection rate, rate index, accuracy and type of errors, frequency of language representation methods, and the list continues. If AAC professionals are not routinely collecting and reporting achieved performance in making critical decisions about AAC technology and intervention, then AAC speakers and families should inquire about having communication performance assessed.

Tools to automatically collect and measure quantitative performance data have been available for a decade. This presentation will include case study examples of how quantitative performance data using Language Activity Monitoring (LAM) tools were used to improve educational and employment opportunities for AAC speakers. Monitoring specific measures based on an individual's skills/needs results in improved individualized treatment plans and long-term performance. The AAC Institute

(www.aacinstitute.org) and ICAN™ Talk Clinics resources empower an AAC speaker to ask the right questions to obtain the performance data - clinical and personal evidence - needed to achieve optimized communication. In some cases, additional intervention and training may be required to obtain the desired outcomes. However, in other cases, individuals may wish to implement a substantial change by considering a more effective language application program or a more efficient user or control interface. Employment is the desire of most adults and influences perceptions about quality of life. Highest performance communication is vital for the best life experience for AAC speakers.

People First of Ohio, an Advocacy Group for Disability

William Adams, B.A.
Vice President, Board Member, People First of Ohio
Portsmouth, Ohio

Good day ladies and gentlemen, my name is Bill Adams, and I'm from Lucasville, Ohio and it's always a honor to be at PEC@ again. I've been coming here since 98, and I always look forward into coming here, seeing old friends, and making new ones, and of course listening to the presentations. I always feel slightly inadequate, seeing so many success stories, of being employed, and I have only been volunteering for the past seven years, but I'm not up here for that now. This year, I kind of wanted to do something different, as you see, I am not alone up here today, I wanted to share a great organization with you that I happened to find six years ago, People First of Ohio. I guess that this culminated a two-year relationship, because we had a guest speaker from the Pittsburgh Employment Conference for Augmented Communicators (PEC@) at our conference two years ago, but I'm getting way ahead of myself. Up here with me today are Sadie and Joellen Hunter, and we are from, as I said before, People First of Ohio, and we are here to talk a little bit about who we are, and what we do in the state of Ohio. First of all, People first of Ohio is a self advocacy group for the disabled, it consist of 24 board members from around the state, and all of us has some type of a disability, but what makes us so unique is that we're the only advocacy group within the state that only consist of people with disabilities. I found out about them back in 2005, I was going to our county's People First chapter, and their director informed me that there was going to be a conference that was going to be held in Columbus, and she suggested that I should attend. When I got up there, I found something amazing, it really felt just like the Pittsburgh Employment Conference to tell you the truth, like this is the place where I belong, because everything that took place, I fully enjoyed it. So at the end of the conference, they held their annual election, and something inside me said, you had a great time this weekend, don't let this opportunity to get on this pass you by, so I ran. After voting, I left to go home, not knowing that they count the ballots on the same day, which I found out that I had gotten on a couple of weeks later through the mail, which I'm so glad that I had decided to run, because it had changed my life. And the real reason why I had ran, was that, it felt like one big family when I was up in Columbus, and that was such a nice feeling to experience, and we are indeed like a family throughout the years. When I first arrive at my first board meeting, my eyes were opened wider to the things that People First does, and that is to do some great and hard work for the state, to try to help to improve lives for the better for the disabled citizens across Ohio. I hadn't seen nothing like that before, really working on legislature materials eventually will come to pass. And to tell you the truth, seeing people that has different types of disabilities, working hard on these legislature materials is very rewarding, because who's better to work on matters that concerns the disabled, than people who are experiencing, and effected by what is going on with their life. And I'm talking about all types of developmental disabilities, and I always had felt throughout of my life, that the disabled community is equal in my

eyes, I've been around all different types of disabilities along my walk of life, and every person who has a disability, is either of brother or a sister of mine. When I am home, I ride the bus for the disabled to get to my work, and I ride with both adults and children, because it's a rural county. And I am thinking about a little nine year old boy who rides my bus, a tragic incident had happened to him when he was just a toddler, and now he's in a wheelchair, and requires total care, he's a brother of mine. So when I'm working with People First, I'm not only working for the better for Bill Adams, I'm working for my brothers and sisters, I'm working for that little boy, who cannot speak up for himself.

And over through the years, we had worked on some serious issues that had made an impact on the state of Ohio. One of the biggest, which was worked on ever since the inception of People First, was changing the name for the Department of Developmental Disabilities, we fought long and hard to get rid of the m r letters. And in the fall of 2009, Governor Ted Strickland had finally signed the bill that changed the name legally. We were chosen for a pilot program to be trained on to do some sexual awareness, we are now eligible to train others on how to be safe, because we all know that predators go after the vulnerables, and Heaven knows, I had heard horror stories at this conference down through the years that made me sick. We do this seriously, but we do have fun with the subject also, we are adults, and lets face it, we clown around when sex is being talked about. But the main thing is that we want everybody to be safe, and to know what to do if God forbid something does happen to them. We teach people to use proper terms when explaining to the authorities what had happened to them, if they were victimized, because if someone says I got touched on my ding dong, courts might throw the complete case out, so proper terms is very vital to put away the perpetrator. Another program that we are involve with, is project vote, teaching people how to vote, and in numerous ways of how they can vote. You never know there are many ways to vote, until you take a two day course on it, knowing who can take you to the polls, and who cannot, which I was unaware of, your employer, a union representative, or, of course, the candidate who is running. But as always when we are taking these classes, we do have fun, a lot of interesting discussions come out of it.

I talked about the group effort that we do, and there are so many things that we do, as putting complicated materials, into people first language, so that everybody could understand, but now I want to talk a little about of how an individual can grow in people first. Sadie is used to talking about a lot about our group, but I'm kind of giving her a break, but don't get used to it, she will be talking about this year's conference later on. That's another reason why I love this great organization, and that is because one can branch out into other areas to help people. About three years ago, we were at a weekend board meeting, and Sadie and Joellen had asked me if I would be willing to sit on a committee that would make a change for the entire Department of the Developmental Disabilities system in Ohio. This committee was called the future planning committee, and it had indeed changed my future in a positive way. As I said before, I live in a rural area, and now I was being asked to go up to Columbus, and work with superintendents, legislatures, and the head for the whole Department of Developmental Disabilities, needless to say, I felt like a fish out of water, kind of slope down in my

wheelchair, didn't want to say anything stupid, which that is one of the things Sadie gets on to me about, and that is, I lack in confidence at times. But after a brief while, I relaxed and started to give my opinion on things. We broke up into four sub-committees to work on different areas that we were wanting to explore, and which that helped to get the things that we wanted, accomplished. And from out of my sub-committee, I started to come out of my shell a bit. We worked on the future's committee for eight months, and from out of the whole committee, we made 33 recommendations, that we would have liked to see changed. But from out of the committee for myself, again it allowed me to expand my horizons, because the chairperson from my sub-committee was so impressed with the work that I contributed, that she wanted to work with me again, if we had the chance. And sure enough, a couple months later, she e-mailed me, wondering if I would be interested in sitting on the advisory board for the Ohio Center for Autism and Low Incidences, or, OCALI. And that is where I am now, plus I'm also on the post committee of the future planning committee, seeing that those recommendations are being worked on. So, I am around working with big wigs across the state of Ohio, something that I never thought of me doing, but I owe it all to People First, because they had got my foot into the door.

Before I turn it over to Sadie, when I started this talk, I said that this really had culminated two years ago, and that is because, just like PEC@, People first holds it's conference every two years. And the last time that I was here, I had asked Bobby O'Gurek if he would be interested if he would be our guess speaker at our conference, because one, I just thought that the conference would love to have him, and two, we are good friends, and I always hate to wait every other year to see him. And he didn't disappoint me, he was great, done a super job, wasn't surprise by that. I also wanted him to see what People First is all about, see what we do. And when PEC@ was coming up this time, I wanted Sadie and Joellen to also see what it is like to come to the Pittsburgh Employment Conference, because both organizations had really made a huge impact on my life over the years. When I had heard that the theme this year was going to be focus on jobs, I thought that it had coincided with our theme last March, cruising into employment, so it went together, and since I had talked about who we are, and what we do, I thought that Sadie might wrap us up with what we did at our conference this year. Because we always have some interesting themes for our conferences, and every year it seems to get interesting and interesting, you always wonder what it will look like, theme wise, and it's up to these two ladies to figure out how are they going to pull it off, the conference committee tells Sadie and Joellen what they want for a theme, and these women just figure out how it is going to happen. For example, for this year's theme, cruising into employment, they had rented a huge canvas of a ship that had literary went from the floor to the ceiling of a convention center, plus other numerous things that had looked like that we were on a ship, so, they are very talented and creative. And without further ado, I want to introduce you to a very good friend of mine, someone who had helped me to open many doors for me that I could assist more people throughout of the state of Ohio, the Executive Director for People first of Ohio, Mrs. Sadie Hunter.

Two AAC Professionals Experience Temporary Communication Disabilities

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Western culture has a peculiar blindness to communication disability. Perhaps it is that we regard communication as such an intimate property of the person as to be a direct expression of the personality and beyond polite notice. Growing up in the 1950's and 1960's many of us saw advertisements for disability organizations featuring a child's walking with crutches. Many people who were unable to speak or use hand signs often found themselves spending unsuccessful years attempting to learn to walk. A moment's reflection tells us that communication is a much more important ability than ambulation. Why this cultural blindness? I do not know.

Socio-linguistics recounts all sorts of measures of how well and under what circumstances and to whom a person communicates. I'm not sure this discipline has yet fully focused on the widespread nature of communication disability. In the 19th century many people on Martha's Vineyard – an island off the coast of Massachusetts -- were deaf because of a recessive gene. Everyone had family members who were deaf, and everyone, hearing or non-hearing, learned to use an effective hand-sign language.

Communicative competence is a term introduced by the anthropological linguist, Dell Hymes (Hymes, 1971). His work has been explored extensively for 2nd language learning and in augmentative communication. Many of the areas he explored are related to augmentative communication, but he does not explore the issue of why there is such a widespread public blindness to communicative vulnerability and disability.

Ervin Goffman (Goffman, 1959) explores how we present ourselves in public. He explores speech disability (Goffman, 1963), but as far as I know, gives no hint about why people do not notice the existence of communication disability, and once noticed, do not know how to handle it.

I would like to begin this presentation by stating both authors have had experiences which in some ways replicate the kind of communication disability studied in AAC. You

see, both of us have spent a lot of time in countries where we did not speak the language at all or spoke it poorly. Reflecting on my experiences leads me to remember how ill at ease and sometimes fearful I felt in many situations.

My first anecdote is about accompanying an elderly and somewhat famous female yogi on a trip to the Netherlands – a country whose citizens are famous for their mastery of English. In Amsterdam American films are shown without subtitles! My friend had serious visual problems owing to a failed cataract operation followed by glaucoma. Let's call her Mrs. M. and say that she was at this time in her life (75+) effectively blind.

Mrs. M. fell down a flight of stairs in the apartment rented from friends in Amsterdam. She had what turned out to be a series of spinal fractures after falling 15 steps. She was in enormous pain and strapped to a medal contraption to prevent further damage to her spine. I accompanied her in the emergency medical ambulance to a nearby hospital. In the emergency room rapid-fire questions were asked of me in Dutch. I couldn't understand the questions. Mrs. M. became more frightened and demanded to know what they were saying because she couldn't see them. The next hour and a half was a humiliating bedlam for me, and a terrifying voyage for Mrs. M.

Soon she disappeared into the bowels of the hospital for tests. I was not allowed to accompany her. I sat in a waiting room with only a few other people for what seemed an eternity. Unable to ask questions, I tried to distract myself by reading Dutch newspapers. It was an awful wait. When a physician returned, he more or less barked out to me the diagnosis – 3 compression fractures, very painful, but not paralytic. Then the doctor disappeared.

Although this experience took place more than 30 years ago, and Mrs. M. lived to be 96, it's hard for me to forget the isolation and fear I experienced. When I am in a foreign land whose language I do not speak, I tend to cling to any person with me who can speak the local language. I often reflect on my experiences as related to what augmented communicators experience regularly.

Another example illustrating how little attention we pay to communication vulnerability took place in Pittsburgh in the early 1980's. I was at a local residential care facility talking to a man with cerebral palsy – let's call him Kevin -- who could not speak effectively, move his arms or feet, but was obviously a thoughtful individual. In the course of our conversation about communication aids, I phrased my questions with care and he signaled his understanding by the look in his eyes. Richard D. Creech, with whom I had collaborated to create Minspeak® in 1980, told me that when he did not have his AAC system, he chose to avoid signaling a direct yes or no. "If you can't explain what you mean by yes or what you mean by no, it's very dangerous to indicate a pure affirmative or a pure negative without the ability to explain."

During my conversation with Kevin the bell rang for 8:00p.m. – the signal for visitors to leave. The director of the facility, a confident senior nurse now in administration, came into the room and told me I should wind down the conversation because the night

procedures were beginning. A cart was pushed into the room, and the nurse's aide pushing it left it in the room, while she went out into the hall to tend to some other task. The senior nurse brought the cart over to Kevin and said to him, "Do you want your orange juice?" Kevin looked away. She looked at his name on the bed and said, "Don't you hear me?" "Do you want your orange juice?" Kevin was frozen stiff with eyes averted. The director was obviously annoyed and began pushing the cart back into the hall when the nurse's aide came forward. The aide said, "Kevin, he don't like no orange juice, it make him sick. He always take milk." Kevin rose up in his bed/chair, waved his arms, and gave an appreciative yelp.

I believe I have just described a situation that conforms to Richard Creech's insight. Kevin couldn't say no, because he risked getting nothing. Kevin couldn't say yes because he'd risk getting orange juice (he has reflux problems with orange juice). The strategy he used was to avert his eyes and act like he hadn't heard the question. Pretty neat, really. He knew the nurse's aide would probably come back and get the cart, and he was willing to risk the director's irritation because she was a person whom he rarely saw. Kevin's strategy worked and I was given an important lesson in how augmented communicators often have to strategize when they don't have access to a good communication system.

I'm going to relate an incident described to me recently by a friend about the behavior of an augmented communicator he knew. They both got into an elevator and an attractive woman – perhaps to be polite -- asked the augmented communicator how he liked the weather. The AAC user turned his head away from the woman and said nothing. After the woman exited the elevator the AAC user said to my friend when he got his head-stick back in place, "I would rather be thought rude than stupid."

We judge people by their speech – intelligence, social class, worthiness in general. We notice a wheelchair, crutches, a white cane, but we do not notice the possibility that our interlocutor has a communication disability. Perhaps the wheelchair, crutches, and white canes are understood symbols but a head stick and a computer mounted on a wheelchair are not better understood. Even if they were understood to symbolize communication disability, I believe we would regard the silence as rudeness rather than a natural adaptation to a situation.

Pretty rough, huh? When I was a young man studying in France, and really couldn't speak any French for my first few weeks, I avoided people's direct glance because I found it embarrassing to be unable to reply. The French, unlike the Italians or Scandinavians, are not very charitable when it comes to butchering their language. French annoyance with bad French is legendary, but Americans are very much like the French. Butchered English is not appreciated on the American street.

I would prepare a sentence over and over again in my head on a 20-minute subway ride to go to my bank. After I told the teller I wanted to deposit or withdraw money, I dreaded the next question. In my first week, the teller referred me to the bank manager to whom I repeated my French question, and he replied "I see you speak no French."

After living in France on and off for almost 3 years, I felt fairly secure in my ability to express myself in basic French and to read academic French with relative ease. When I decided to spend the summer months of 1978 at the University of Valencia on the Mediterranean coast of Spain, my Spanish was shaky to say the least. I had never studied it formally before that summer, but I was going to be teaching beginning Spanish as part of my French and Latin schedule at the high school where I taught in the U.S.

I felt humiliated speaking really bad Spanish to people on the street, in stores, my landlady, *etc*. I sought out a couple of American friends and tried to hang out with them. Then I made a discovery – Spanish people could understand my French better than they could understand my broken Spanish. It was a bad discovery for me. Gone was the humiliation of being an illiterate American – I just spoke to people in French when my Spanish broke down. I actually did this a lot and it slowed my developing decent Spanish. It was foolish on my part, but it saved energy and ego.

The only benefit I derived from this experience was my ability to understand the behavior of a young AAC user who was part of the famous Westinghouse project where Word Strategy® -- the father of the Unity® software – was developed. There was one adolescent boy who was learning Word Strategy® and making good progress. However, when he spoke to me, the author of the program he invariably used one-handed American Sign Language to communicate with me. Even after I told him many times that I couldn't understand his signs and rapid finger spelling, he would still use them first in any conversation with me. In each conversation I had to explain or perhaps admit that I couldn't follow him. Only then would he use his voice output system to communicate with me. Why in the world was he using hand signs with someone he knew could not understand hand signs? Well, strangely enough, I knew from my own experience why he was withdrawing to a language where he felt confident and I had only a rudimentary knowledge.

Let's now explore communication vulnerability and disability issues related to the world of work. Employment provides not only an income and meaningful activity but contributes to increased self-esteem and feelings of self-worth, as a contributing member of the community (McNaughton, Light, & Arnold, 2002; McNaughton & Nelson Bryen, 2002; McNaughton, Symoms, Light, & Parsons, 2006). It is also a source of social contact and offers chances to make friends with colleagues and to interact with others who may share similar interests or who are working towards similar goals. This holds true for all who work, whether or not they use augmentative and alternative communication (AAC).

Currently, people with lifelong disability, including those who use augmentative and alternative communication (AAC), experience low rates of employment. Some have found that self employment is a solution although this may reduce opportunities for social engagement (McNaughton, et al., 2002; McNaughton & Nelson Bryen, 2002; McNaughton, *et al*., 2006). Others seek to volunteer as a way of contributing to society.

A recent study of 24 adults who use AAC and who volunteer indicated that volunteering offers a means of contributing and at the same time educating the community about AAC and disability (Trembath *et al.,* 2010). The results of this study indicated that a lack of effective communication systems and appropriate support, impacted negatively on the experience and reduced opportunities to volunteer. Indeed, adults who use AAC are at risk of exclusion from the work or volunteering contexts which are important way of contributing to society (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006) because of their communication disability. Effective communication, reliable AAC technology, accessible workplaces, peers with positive attitudes towards disability, vocational skills, good transportation, and attendant care services are all key factors in gaining and maintaining employment (Bryen, Potts, & Carey, 2007; McNaughton, Light, & Gulla, 2003). An additional, although often overlooked, issue is the ability to manage eating and drinking with dignity. In some work situations, important discussions that may lead to change and new direction or where new alliances are formed, are held over coffee or a drink after work. Employees who use AAC and who experience problems with eating and drinking may feel disadvantaged and unable to participate because eating , drinking and talking, in particular managing finger foods are too difficult and messy. A woman who uses AAC whom I know complained that as she never goes to these functions, including the office Christmas party, she is no longer invited and feels excluded and sad to miss the social occasions (Balandin *et al*., 2009). She feels it may be considered rude to refuse food, yet cannot eat independently without choking and coughing. This is embarrassing for her and frightening for others. If she were on a diet, she would refuse finger food and no one would raise an eyebrow. Why is it so difficult not to conform exactly in every situation? Can it be because it is so important to be seen as fitting in and we feel we must do as others do in order to accomplish this?

None of this is new to PEC@ audiences. Indeed, I think it was probably at an early PEC that the late Jim Prentice discussed what having a job meant, not only in terms of the joy and independence it brought but also the costs at a personal level. His comments have been repeated by others including adults in Australia, such as John Morgan (Balandin & Morgan, 2001) and Meredith Allan (Allan, 1999) to name but two.

If we consider that employment is one of the best examples of how an individual is integrated into and contributes to society, we must continue to battle to ensure that people who use AAC have equal opportunity in the work force and are employed in work where their worth is recognized and they are valued for the contribution that they make.

Of course, this means being given the opportunity to contribute through employment. This brings me to my thoughts on communication disability and work which I have had cause to reflect on having been working in Norway for three years now. When I arrived I did not speak Norwegian at all. I had hardly ever heard it spoken and dreaded meeting people because apart from language difficulties, their names were so foreign that for me it was like trying to remember nonsense words. Consequently, I never went to the lunch room or to social situations and as a result was seen ‘stand offish’. In other words, I felt excluded, but my colleagues saw me as excluding them! Why did I just not say, “Sorry I find Norwegian names almost impossible to remember, so I have to practice. I know you

but can you help me with your name?" For the same reason, I guess, as it is too hard for my friend to attend a function and say no to a sausage roll, we feel that we must fit in and do what everyone else is doing and there are certain social norms, eating with others socially, recalling names that we feel we must fulfill.

How shocking then, to find that having achieved employment, the dream becomes if not a nightmare, certainly a disappointment, because of communication difficulties. It is not so easy to contribute, feel valued, and maintain equality with other workers when you have severe communication impairment or use AAC. Nevertheless, as we know from stories that we hear at this conference and indeed from what we read, work is an achievable goal, but not by as many who are ready and have the skills to do a good job. We also know that working with a communication disability sometimes comes at a heavy price and some people have found the price too high to make work tenable. I wonder if sometimes this is because of an overwhelming longing to conform on the part of the person with the communication disability coupled with limited understanding of communication disability on the part of work colleagues. People laughed when I confessed my problem with names and said that now I should understand why they avoided writing English- also a journey into what may look like a series of nonsense words.

Other things I experienced that are similar to stories recounted by those who use AAC include that working longer and harder than anyone else to demonstrate that you are good enough is tempting, but is a slippery slide to exhaustion and may give the impression that we who have communication problems do not see ourselves as equal to other employees. We may be grateful for the job inwardly -- we are employed, and like everyone else, because we have the skills to do the job. Thus, a sense of gratitude is probably misplaced.

I think it is important not to promise to do more than is reasonable, and the answer to this may be to look at the employment contract. If you are doing what you contracted to do, you are doing a good job. Certainly that will be what most of your colleagues are doing. In my experience many people at work see work as a means to doing other things, including having fun when not working, rather than an end in itself.

Is it important to use the phone when there is email with a range or writing programs, or for those of us who are language challenged, to Google translate?
If you are deemed unable to communicate in the work place the possibilities to contribute may be ever decreasing. Being angry and frustrated does not seem to help. Being a good colleague and building alliances with coworkers may help a great deal. When I was struggling with the language at work I assumed that everyone else was in control of their own work and satisfied. How surprised I was when I eventually ventured to the tea room to discover that this was not the case at all. What had happened to my common sense? I know that no one is happy in their job all the time. Everyone experiences frustrations and difficulties, yet when dealing with my communication disability it seemed as if it were only me.

To be talked down to or ignored because you are not quick enough to communicate is a bitter pill to swallow. Yet in fact, most of us swallow these pills from time to time in the work force. Sometimes confrontation works but not always. Working strategically and remembering that no job is perfect all of the time may be a sweetener. It may also help to consider that anyone who has a communication difficulty is likely to experience problems at work and that this is common beyond people who use AAC. Indeed, I was helped greatly by what I know of the experiences of people who use AAC, as this helped me to focus on what problems were a result of communication difficulty, which ones were just 'part of the job' and what strategies I could use to manage these. I certainly reminded people that I was not deaf and had to resist reminding people that having a communication disability is not indicative of having a cognitive impairment.

It is important that we continue to share our experiences and support each other to ensure that people who use AAC and those who have communication disability have the same employment opportunities as their peers. It is also important to continue to share personal stories and conduct research so that we build knowledge about what works, what battles can be won and when it is wisest to take a deep breath and move on.

Finally, from my own experiences of a life time of work with and without a communication disability, it is important to find people at work you can trust and who will support you if you need help. I now also believe that it might be useful if all those who work in the field of AAC, including speech-language pathologists and vocational guidance officers have a spell at working in a place where they cannot speak the language -- preferably with someone who uses AAC as support colleague and mentor.

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Don't Feel Like an Unmarked Paper Bag -- Some Job Tips

Snoopi Botten
DECtalk Musician
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Going to job interviews can make you feel like an unmarked paper bag. You are ready to deliver what ever a situation calls for, if the wind blows the right way and lands you a job. And this economy, I'm sure many people feel this way. I mean you can only do so much with a resume, right?

If this is how you feel, you need some tips because finding a job involves some preparation before you even schedule an interview. It involves learning a little about the company, what they do, and how you can fit in. You need to be able to say what value you alone can bring to the company, without coming across as a know it all. This puts a special marking on you so you are no longer just another paper bag waiting for the job market to send you somewhere. And if they look deeper inside of you, you need to have a few fireworks ready to set off to inspire the employer to hire you. Any company needs employees that can help the company move forward. And if my talk alone doesn't inspire you, my song will. And the next interview you set up, go expecting to get hired, because YOU, are a firework!

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Why We Are Having a Play Tomorrow

"Step by Step," CBS Morning News
Gregg Mozgala, BFA, Actor, Writer, Dancer
New York City, New York

(Editor/Chairperson's note) We are having a play tomorrow because your conference chairperson read an inspiring, sad, belly-laughing essay by an actor with cerebral palsy who was featured on *CBS Sunday Morning,* in January 2010. It is the story of an actor with a disability receiving national reviews as a dancer! in a dance theatre piece based on Nijinsky's ballet, "Afternoon of a Faun." *The CBS Sunday Morning* piece was inspiring, especially because of the interviews of Mr. Mozgala in the process of becoming a dancer. I decided to look him up on Google and encountered an essay he had written on a disability blog from the Alliance for Inclusion in the Arts – Promoting full diversity in theatre, film and television (http://inclusionin thearts.org/projects/national-diversity-forum/opinion-pieces/gregg-mozgala/). Mr. Mozgala describes his personal experience, being an actor with a disability, and asks a question, "Other minorities have achieved inclusion through film, theatre, and the arts – why not a disability literature in the arts?" I was moved by his essay. He asks the question so well that I asked him in a meeting in New York last fall – "Why not a play about AAC at PEC@?" Mr. Mozgala agreed to be its author and has made several visits to Pittsburgh to interview actors and develop an amusing 10-15 minute play about complex communication needs – AAC. Now let's see the 6 minute CBS Sunday Morning News Clip from January 2010.

An Anecdote

Gregg Mozgala, Actor/Playwright, 2005-2006

Shortly after I moved to New York City to pursue acting, I was fortunate to find an agent interested in taking me on in a freelance capacity. I had been seen by several agents and industry professionals during my senior showcase at Boston University, but this was the first to take an interest in me despite—or maybe because of— my disability. Although not as good as signing directly with the agency, it was a step in the right direction, an avenue to legitimate, paying work. That spring the Berkshire Theatre Festival was auditioning for an upcoming production of *This Is Our Youth* by Kenneth Lonergan. I was a fan of the play and thought I was right for one of the leads. I decided to be proactive and call my agency to see if they would assist me in securing an audition. I explained the situation and the agent refused to entertain the idea, stating that I was wrong for the part because, "They were looking for normal guys."

I have a mild form of cerebral palsy resulting in an inward rotation of my hips affecting my gait. I am not in a wheelchair, do not need crutches or canes, and if sitting in a chair or standing still one would not be able to tell that anything was physically wrong with me. Basically, I walk funny. This agent, however, who had seen me perform, even met

me personally, was refusing me the chance to audition for an able-bodied role because I wasn't *normal.* Subsequent conversations have reaffirmed his way of thinking and it became clear that he would only send me out for "appropriate roles," i.e., *crips and retards*.

In the six years that I've been living in New York City, I've been auditioned for several characters with disabilities. Yet, I can count on one hand the number of times the "agent" has submitted me. I've found consistent work through relationships I've cultivated on various shows. Often, I'm randomly contacted by a company or casting director referred to me when looking for an actor with a disability. Now, you may be surprised to discover there are not many parts out there for twenty-something white males who walk funny. This is an image conscious industry after all, and it has been my experience that when people ask for an actor with a disability they expect the wheelchair, the missing limbs, the guide dog, the drool, and the spasms. I have not booked a single one of these jobs. I believe I haven't been successful booking work at a high level, not due to lack of ambition or talent, but because I feel, that I am "not disabled enough."

The following is a typical exchange:

Casting Director: …So you're not in a wheelchair?

Me: No.

Casting Director: Or on crutches?

Me: No.

Casting: Oh, I see. Let me call you back.

(A few minutes go by)

Casting Director: Would you mind using a wheelchair?

Me: Not at all.

Casting Director: Great. Come on in and we'll see what happens.

What happens is that the part goes to an actor who is deaf or hard of hearing, an actor who uses crutches or a wheelchair—actors with more severe, visible disabilities—or, as is more often the case, to able-bodied actors with more professional credits. This is an all-too-common occurrence. I do not believe that I or any other actor should get a part merely because he or she is disabled. I believe that the part should go to the best actor for the role. Currently, actors with disabilities do not have as many opportunities to audition for any role, much less high-visibility roles in front of key decision makers within the industry.

A few months ago when I got an email from an actor I was in a show with a few years back telling me that a large, well-known casting office based in New York City was looking for an actor with cerebral palsy who could portray a teenager for a feature film I was a little gun shy. The casting director was having trouble finding suitable actors to audition for the role. They wanted to cast appropriately and I fit the criteria. My friend passed on my name and told me that I should contact them for an audition.

After reading the script for the film, about two friends in a small southern town, one of which was in a wheelchair, I knew I couldn't walk into the audition room and risk losing one more opportunity before I even opened my mouth to speak. I decided to *crip it up.* I borrowed a spare wheelchair from a friend and wheeled my way over to the casting office. I was the only disabled person in the room. I absorbed and internalized the usual looks from people, magnified ten-fold because of the chair. If people didn't know how to respond to me before, they certainly were politely terrified by the presence of a real-live, visibly disabled person in their midst. Upon seeing me, the casting director quickly ducked into an associate's office and whispered harshly, *"Why didn't anyone tell me that there would be someone in a fucking wheelchair here today!"* Had anyone read this script?

My time came and I went in the audition room, slated my name, and read my sides. I thanked them for the opportunity and went on my way thinking that would be the end of it. A few weeks later I received a call back with the director who proceeded to ask me specific questions about my disability. With a slight panic, I realized these people had no idea that I could actually walk! I had to decide right then to either reveal my ruse or continue playing the part that I had created. I chose the latter for better or worse. A month went by and I was convinced that I was out of the running. I then got a call for a second call back with the director and the executive producer. This was actually working! Not only was I still in the running, I was a serious contender. The lead in the film had already been cast at this point; a blond-haired, blue-eyed, all-American looking young man plucked straight out of Central Casting. He introduced himself and exclaimed, "Cool, you brought your own chair." I couldn't tell what enraged me more, his easy good looks or obliviousness to the ignorance and prejudice his comment contained. The scene we were about to do required a heated exchange between the two friends, so I was able to bring the emotion into the work. I left feeling I gave one of the best auditions of my life.

I didn't book the job. True to form, the part went to an able-bodied actor with more professional credits. I can't help but wonder if my attempts to get the job by any means necessary backfired. Was it possible that I didn't get cast because the director or producer thought of me as *too* disabled and didn't want to risk the perceived expense or effort to deal with me on a film set? I'll never know.

What I learned from this experience is that people in power in the industry, the ones who make decisions regarding casting and greenlighting of projects suffer from a lack of imagination. However, the lion's share of the blame for this myopic world view should not fall on them, but on us. Disabled people have spent centuries allowing themselves to be defined by others. I know that we can't wait for people's perceptions to change. We

have to actively change them.

I believe theatre offers the best venue for that to happen. Every other large minority group that has broken through to mainstream American culture; African Americans, Asian Americans, Gays and Lesbians, Women, Latinos, etc. all used theatre to challenge and change perceptions to carve out a place for themselves. Hollywood and major studios didn't take notice until these people started showing up on stage. Why can't we do the same? Why *aren't* we doing the same? Where are our August Wilsons, Tony Kushners, Jose Riveras, and Wendy Wassersteins or Paula Vogels? Where are the plays that show disabled people living, loving, laughing, and struggling with the human experience? If we want our stories told, we have to tell them. We should be screaming at the top of our lungs, pounding our crutches against the ground, burning rubber with our wheelchairs to break down doors and remove barriers. We need to make our stories known. Offering incentives for studios to cast disabled actors, offering incentives for writers to educate themselves and write about people with disabilities is all well and good, but why not the people who have actually lived the experience? We need to cultivate talent from within and change the landscape with our own work, sweat, and imagination. Until we do, we'll be waiting for someone else to tell us where we belong. Haven't we waited long enough?

Getting Ready to be a Grown-up: Jobs and Teens

Robin Wisner
Parent Support Liaison
AAC Institute

Board of Directors
Always On Our Own

Caleb Hurd, 8th Grade
Joshua Hurd, 8th Grade
Fairview Middle School
Erie, Pennsylvania

Have you ever wondered what a teenager who uses AAC in 2011 thinks about jobs? Joshua and Caleb Hurd talk with their mom about the jobs they do at home, their school experiences that help them explore possible job ideas, and their job interests, both the "practical" ones and the "dream jobs".

Josh and Caleb are entering 8th grade in the fall of 2011. Eighth graders at Fairview Middle School can choose from a wide variety of special nine week classes that range from the typical art, home economics and foreign language classes to computer aided drafting, video production and introduction to robotics. When presented with this wide array of choices, Josh and Caleb had very definite opinions about what they wanted to do. Some of their choices involved advocating for what they wanted. Josh and Caleb, along with their mother, will talk about how they did this.

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PEC@2011
Employment: Focus on Jobs

Platform Presentations

Day 2

As a person with a disability, everything takes me much longer than people without disabilities and … I'm often paid by the hour… The question is, if something takes you five times longer because you have a disability, should you get paid for the entire time you worked or only part of the time? …
… if I can get the same product or service for five times cheaper somewhere else then I am going there instead of you. You can kick and scream all you want saying it's not your fault you have a disability. The bottom line is, if I can't afford you, I can't hire you. … I have found it better to only bill for part of the time you work is respect…
I never openly share with my clients that I only bill them a portion of what I work. In fact, only a handful of my 36 clients know I do that.

("Running My Own Business…" -- Brad Whitmoyer)

Life on Life's Terms: Living As An Augmented Communicator

Panel Discussion Participant
Ami Profeta
Elkins Park, Pennsylvania

Good morning, my name is Ami Profeta, from Elkins Park, Pennsylvania. I am working as an Administrative Assistant for Allied Barton Security Services. I entered all of the new security guards Safety Orientations and On the Job Checklists in to the Database. Also I compile a monthly report for off site visits for the managers at a single site in an Microsoft Excel Spreadsheet.
I have a brother name Ben, and a sister name Rachel. Rachel works for American Jewish World Service. Ben works for Blackrock which is an investment firm.
My mom works for Black Rock. She is Vice President of corporate services.
My dad owned Dave's Best Limousine Services.
My dad helps me to get ready for work. That would include giving me a shower, dressing me, preparing breakfast, and feeding me. Also, he drops me off at the train station.
I have two assistant name Valeriy. He works in the Evening shift. Scott comes to my office and he gives me lunch. Also, he is my backup when Valeriy goes away.
Please join USSAAC which stands for United States Society for Augmentative and Alternative Communication. We provide *SpeakUp* Magazine quarterly. I am the mid-Atlantic region representative.
I am an Ambassador for Prentkie Romich Company.
I have been doing the shows with my synagogue like The Sound of Music, The Wizard of Oz, Once Upon a Mattress, Oliver Twist, Suessical, Oliver Twist, Bye Bye Birdie, and Children of Eden. I was in the chorus. The directors treated me like everyone else. Also, I sing with the men's choir once every month at services. I sang with the Kardon chorale. We preformed at different functions in the Philadelphia area.
I was asked to do research on a documentary called "A Hero in Heaven for a soldier name Michael Levin z'l. It was a privilege and a honor to work on the documentary for his Family and Friends.
I am a single guy who is looking for a girlfriend.

Life on Life's Terms: Living As An Augmented Communicator

Panel Discussion Participant
Paul Garrick
Scott Township, Pennsylvania

Good Morning, I am Paul Garrick. This year's presentation would be on what I had to keep my occupation that I held for twenty years!! Yes, you heard me right in the current times you rarely know anyone who held her or his position for that period of time.

People change their professions or accept new roles in their place of employment, but in the twenty years, I have seen things occur around my occupation of maintenance assistant / sacristan for a local church. For example, individuals come and go and I had adjusted to the numerous bosses and supervisors and the way they do the tasks that are required with each boss change. I had to take a cut to keep my occupation. After the new priest came and looked at the situation that the church was in and the way that the economy was, the pastor decided to decrease my hours. This time, I was not the only one that was affected because with this priest's cutbacks, he nearly eliminated everyone's jobs. With the pastor's decisions, I just decided to accept them and see where his decisions would lead to, so I decided to give him a year, even some of his decisions were hard to accept.

In that year, I sat back and watched how the pastor would get all of the work done that is left behind from the positions that he decreased. The priest subcontracted some of the work out and asked volunteers to do the rest of it. Also, I watched the shape of church decline. As I watched what was happening, I did some serious thinking about my future in the year that I gave my boss. No, I am not going to do anything, like quit, if my situation does not improve, I am just saying that I will be examining other avenues to support myself instead of being dependent of my current employment situation.

A part of my thinking process, I thought, what could I do if something like this occurred. I did not get called back for the summer, so I came up with some ideas and there are as follows.

1. To find another job like at one of the stores that are in walking distant or pursue any another job prospect that I see in my travels or someone tells me about.

2. Go back to where I got assistance from and got my current employment or to an agency like it.

3. Take one of my ideas and turn it into a small business -- mainly something that I love doing.

Since, I was not called in for the summer months at the local church by the pastor… I am taking that as a sign that I should begin to consider to examining the another avenues that

I have and really follow up on all of the leads, not matter how busy I get and leave my current occupation because I feel that the employment situation, I am in could be eliminated too easy.

Before I say "Thank you for listening to me", I need to take my own advice and follow up on something that I said earlier. " Examine all of the avenues" out there. Right now, I am in a position that I can take advantage of like our old Pittsburgh Employment Conference friend, Mr. James Prentice did. As a closing of his presentations, Mr. Prentice took advantage that opportunity to thanks us and market his business and himself. As an a tribute to him… I would like to market myself as individual who is looking for any opportunities to improve my employment situation. If anyone knows of any opportunities to help me with my employment situation, let's talk during the conference.

Thank you.

Life on Life's Terms: Living As An Augmented Communicator

Panel Discussion Participant
Jennifer McIntosh
Keene, New Hampshire

Hello. My name is Jennifer Mcintosh. I am 25 and I have Cerebral Palsy. I use the ECO2 point with my eyes but I call it "pinkie". Prior using this, I had an ECO which I had to used a switch next my head. I used the block scanning and it was very time assuming. Now, I can type a lot faster. But, it did take practice. Since I was in preschool, I used a switch and I am having to learn a new skill. My family started to communicate at young age. They had to spell out the abc and I looked up when they had the right letter. My granddaddy played games like scramble I could learn to spell.

I am going to Keene State at New Hampshire. My major is psychology. I would like to be an advocate for children with disabilities. I am thinking about be coming a Senator. I am using my augmentative communication device to talk in my classes. Last year I had a public speaking class. I think other students thought I was crazy to take that class but I gave my first speech they were amaze!

I got a job with monadock demenal services. I am a training assistance. Right no, I am planning a training on how augmentative communication device can improved lifes of children with disabilities. I am telling my story to

An augmentative communication device can open a lot of doors for people with disabilities. Thank you for letting me speak today.

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Life on Life's Terms: Living As An Augmented Communicator

Panel Discussion Participant
Jessie Jackson
North Wilkesboro, North Carolina

My name is Jessie Jackson, I am 19 years old and I have a disorder called GM-1 Gangliosidosis Type 2. It took my family over 15 years to learn what my disorder was and during that time we all watched what seemed to be the world as I knew it slowly falling apart. I went from what seemed like a typical child to a non-verbal teenager in a wheelchair most of the time without knowing why or how to stop it. Now along the way the one thing I was told over and over by my parents was "Can't never could..." and I quickly learned "can't" was not an acceptable word in my house! When I would lose an ability to do a task rather than give up I was taught to find a different way. "When life shuts a door....open a window....." was heard a lot over the years! I have grown up doing all the things any kid would do and alot of things some kids never have the courage to even try----I dance, I sing, I climb on climbing walls with my friends, I go to concerts, I ride roller coasters, I ride horses, heck I have even rode in a hot air balloon! Just because I have a disability does not mean I cant or I don't! It simply means I might have to find a different way and honestly the view from the window is often much better than it was from the door anyway! So don't let others ever tell you it cant be done ---- just find your own way and discover your own happiness! Thank you for this chance to be a part of this panel at the PEC...."public speaking" just another item to add to my list of things most people would assume I cant do that I can proudly know ----YES I can and YES I did!

Running My Own Business

Brad Whitmoyer
Delaware, Ohio

Hello, my name is Brad Whitmoyer. I am the owner of BBRADLEY.NET and have owned my own business since 2003. The decision to start my own business really came out of necessity more than a desire. Some of you may already know me but most of you probably have never seen or heard of me so allow me to give you a little background information about myself.

I am currently twenty-seven years old and have cerebral palsy. I have two older brothers and one younger who I believe are one of the reasons I am who and where I am today. When I was growing up, as you can imagine with four boys and a father, we were pretty competitive with each other and with others outside of our family. Two of my brothers played sports throughout most of their childhood. Not only did they play organized sports, they also played in the back yard with neighbors and friends. This is where they were most influential in my life. Any time they would play a game, they would always try their best to figure out how to include me. When we played football, the rule was if the ball hit my body or my wheelchair, it meant I had the ball. It might sound mean or cruel but I loved every minute of it. It was these moments that provided me with some of the most important life lessons and skills that I believe a person needs in order to have a successful business. Some of these include competitiveness, team work and, probably the most important, coping with defeat.

While playing sports with my brothers and friends was very beneficial for my character building, equally important was the times I couldn't participate. As I said, my brothers always tried to figure out a way to include me in whatever they were playing but sometimes it was simply not possible. When this happened, they went ahead and did it without me. This might sound mean but, honestly, this was another crucial lesson I feel people need to learn and it goes right along with coping with defeat. It is the ability to make sacrifices. While this is very important for anybody to learn, it is even more important to people with disabilities.

I'm supposed to be talking about running my own business so let me tie all of this into how it has helped me build my business into the success it is today. I started my business because I wanted a job so I could start providing for myself and stop relying on assistance from others, including the government. Throughout high school, all I wanted was a part time job. I went to a couple of employment agencies who helped people with disabilities find jobs. Every time the conclusion was, I'm good with computers so I should go to college, get a degree in computers and then look for a job. So I started college and very quickly found out most of my classes were going to have nothing to do with computers. So while I was taking music history and psychology classes, I decided to start a business building websites. One weekend I asked my mother to take me to the computer store and

bought a four hundred dollar computer to use as a server. A week later I was up and running.

I started my business with a couple of key ideologies in mind and they all revolved around the idea that any amount of money was worth the effort, no matter how little. As a person with a disability, everything takes me much longer than people without disabilities and in my line of work, I'm often paid by the hour. This raises an interesting predicament and question. The question is, if something takes you five times longer because you have a disability, should you get paid for the entire time you worked or only part of the time. Obviously you have to make that decision for yourself. I can tell you that I have found it has been much more beneficial for me to only bill for part of my time.

I have broken this down to two main reasons. The first is very simple logic of, if I can get the same product or service for five times cheaper somewhere else then I am going there instead of you. You can kick and scream all you want saying it's not your fault you have a disability. The bottom line is, if I can't afford you, I can't hire you. The second reason I have found it better to only bill for part of the time you work is respect. I never openly share with my clients that I only bill them a portion of what I work. In fact, only a handful of my 36 clients know I do that. The ones who do find out have great respect for me, which in turn gets them to refer other people to me.

I believe that my ability to make logical decisions and not just think about what is fair to myself is one of the main reasons my business has been such a success it is, and will continue to be. I would like to thank you for allowing me to speak to you today. I will now answer any questions you have.

The Rights of People with Communication Disabilities in Traveling

Richard Devylder
Senior Advisor for Accessible Transportation
U.S. Department of Transportation
Washington, D.C.

Transportation is a crucial resource that directly impacts activities across areas of employment, education, recreation, social services, health care, and general civic participation. In July, we celebrated the 21st Anniversary of the Americans with Disabilities Act (ADA) and in September the 25th Anniversary of the Air Carrier Access Act (ACAA). The ADA and ACAA civil rights obligations requiring accessibility in services apply to providers whether or not they receive Federal funding. Among providers receiving Federal funding, civil rights obligations apply to both direct recipients and subrecipients. Despite the advances we've made over the last two decades, we still have a long way to go before our country is universally accessible. The U.S. Department of Transportation is committed to ensure that the functional needs of all people are taken into account during transportation planning and will appropriately enforce laws when they are broken.

A Tribute to James Prentice

Al Condeluci, Ph.D.
CEO, United Cerebral Palsy Association of Pittsburgh
Pittsburgh, Pennsylvania

Don Jones, B.A.
Board of Directors
SHOUT
Wilmerding, Pennsylvania

How do you describe a man such as Jim Prentice – hard-working, funny, relevant, informed, courageous, responsive, social, committed, caring, pioneering, humble: All of these descriptions fit, and more. To know, and connect with Jim, was to have a friend who would be loyal, understanding, and present. Jim was the kind of man who would appear to be serious and intense, and then come back with a dead-pan joke that would crack everyone up. He was a man who transcended his disability – came to use his wit, wisdom, and personality to turn people around – to get them to a further perspective. I first met Jim in 1973 when I became associated with UCP of Pittsburgh. My assignment in these early years was to be an "advisor" to a social club known as the "Pittsburgh Rivals." This was a group of men and women with significant disabilities who wanted to take advantage of life and typical community experiences.

Now you have to understand that in 1973, people with disabilities, especially significant disabilities, were rarely in the community. Most folks were either stuck at home, or in institutions. There were blatant architectural and attitudinal barriers and limited tolerance. The Pittsburgh Rivals challenged these norms.

The "Rivals" were hell-bent on being a part of the community and to change the collective thinking. Even though I was to be an "advisor," the truth is that the "Rivals" were advising and changing me. As I came to know these men and women one member of the group stood out. It was Jim Prentice. I immediately took to this sandy-aired, thin man who used a wheel chair and communicated with a spell-board. As we would talk, I was amazed at his intellect, and humor.

In these early years the Rivals traveled and socialized in wild and mundane places. We visited New Orleans, New York City, Las Vegas, Toronto, Orlando and the like. We joined a national group called the AHA (Adult Handicapped Association) and began to learn and explore advocacy and policy issues. We had meetings in Harrisburg, and Washington DC, and began to push and cajole the system.

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In front of all these trips and activities was Jim Prentice. He was a leader and a follower and never ceased to amaze me with his everyday approach. When we faced discrimination or ignorance, Jim would not get mad – he just kept moving forward. He loved to drink, dance, and socialize as well. He knew how to blow off steam. In fact, when Jim had a bit more libations than he should have, this man who could not talk, was able to sing to the songs of the moment. It either defied logic, or was a manifestation of my own over-libation, but together we did a lot of singing – and even harmonizing in these many social situations.

As our social skills developed, so did our advocacy and work skills. Jim Prentice went on from those social experiences to become an augmentative communication user, and built more and more social relationships that led to him starting his own printing business, and then being hired to work for Westinghouse. At the same time he began to join Boards and Advisory groups. He came on to the UCP Board, as well as the Shout Board. He continued to make his mark.

But as I look back on the impact of Jim's life on all of us, it was his social skills, and connections that positioned him to achieve the many things he did in his life. To me, this was the secret of his success.

Sociological research shows clearly that our "social capital," the relationships in our lives, is the key element to life success. We know today that healthfulness, happiness, achievement, advancement; even life expectancy is tied to social capital. Quite simply the more social capital we have, the more successful we are.

This was certainly true for Jim. He developed friends and relationships in so many ways that he was destined to be successful. And so here we are today, some 2 years since his passing, marveling at Jim's impact and contribution to our field, his community, and to the movement for full human rights and involvement. Yet, it was his social connections, his social capital, which was at the root of Jim's success.

If Jim was still with us, I wonder what he would make of this kind of tribute. I don't think he would consider himself to be courageous, or a pioneer. Rather, I think Jim would say that he was a man who, in spite of the disability realities in his life, saw the importance of relationships and what they can do for us all and worked to not only build friendships, but to be a trusted and loyal friend back.

This, I believe, would be Jim's final lesson to us all.

Poster Child for UCP spends time with David L. Lawrence, Mayor of Pittsburgh.

A handsome devil even back then.

When ambulation was more important than articulation!

Standing up for Mary.

Going for a spin in winter time.

Having fun in Steubenville.

Too many awards to count.

Women find me even more irresistible when I'm intoxicated!

Dr. Stephen Hawking walking the dog.

A Tribute to James Prentice (cont.)

Al Condeluci, Ph.D.
CEO, United Cerebral Palsy Association of Pittsburgh
Pittsburgh, Pennsylvania

Don Jones, B.A.
Board of Directors
SHOUT
Wilmerding, Pennsylvania

When I was asked to write a paper on leadership and how it pertains to Jim Prentice, I started to think back on my first experience with leadership. I was eleven years old in the fall of 1959 when I joined the Boy Scouts. The troop I joined was composed of boys with physical disabilities, and it was sponsored by Allis Chambers, a company that made heavy construction equipment and electronic devices. The troop had been in existence for about eighteen months when I read about it in the newspaper. Attending my first meeting, I was assigned to one of the troops' two patrols. There I met John Campbell who was a year or two older than I was who the patrol leader. John wasn't bigger or older than most of the other fellows and his parents' income was probably on the same level as that of every other troop members' parents. When he spoke, however, everybody in the patrol gave their rapt attention to him. I don't remember him having to explain anything more than once. The scouts in his patrol seemed to be able to grasp everything he was teaching them right away. Johns' rank was considerably higher than most of the other scouts; he was a life scout whereas most of the other troop members were either second or first-class scouts. As time went on John rose to eagle scout and I rose to star scout. Other positive circumstances developed; Our little troop that began years ago grew in numbers and we started to participate in activities with other troops. We weren't just the troop for disabled scouts anymore. When John made eagle scout he was offered the opportunity to become a troop advisor which is an opportunity few scouts obtain. I was very flattered when I was nominated to take Johns' place when he moved on to his new position with the scouts. I wondered, however, why they wanted me when there were others who had joined the patrol long before I did. John must have heard my mumbling about that to myself because I remember him saying to me, "I didn't know why they picked me for patrol leader at the time either. Then he went on to say, "You weren't around when we had our first meeting. It was nowhere near as formal as it is now. One procedure we had to go through, however, was the election of officers in order to be recognized as a troop. We voted for one another by raising our hands whenever our names were called out for different offices. When it came to patrol leader I guess I got more hands than anybody else". This struck me as being odd that he would say this because until that time I always thought of him as a natural born leader. I came away with the idea that leaders have some quality in them which stimulates others to put their trust in them to accomplish goals even if the individuals don't necessarily begin by seeing

these traits with in themselves. As the years passed John and I attended the same high school with him being two grades ahead of me. After graduating John matriculated Pitt University and obtained a doctorate in history. This was back in the nineteen sixties before there was the "Americans with Disabilities Act", attendent care, Access, curb cuts or anything else that would have made it easier for a person with a disability to advance their station in life. The last time I heard from John he was doing historical research for various organizations throughout the United States. After the last time I saw John I remember thinking that I would probably never meet anybody with his type of fortitude. A few years later, however, I met Jim Prentice who proved that I was wrong.

After graduating Edinboro University and before I obtained my first chance for employment with the Three Rivers Center for Independent Living I was encouraged to take Classes at United Cerebral Palsy . U C P not only taught how to live on your own and how to be an integrated and productive member of society but also the best Method to promote ones' skills and talents within the job market. It was also recommended to me by my former physical therapist from high school that I try to obtain one of the new communication devices which were being offered to people with speaking difficulties. She explained that since my friends and acquaintances could understand my speaking voice in most situations it was all right to use it to socialize it would never make it in any business environment, though, where immediate and one hundred percent clarity is mandatory. When I explained that I wanted to be more independent and to find a communication device that would improve my employability the people at United Cerebral Palsy said that they would see what they could do for me. United Cerebral Palsy called my house a few days later and I was told that I had been scheduled for classes starting at the beginning of the following week. Sometime between my classes on either my second or third evening at UCP Fred Enck who I believe was the executive director of the organization at the time asked me who I was. After I told him he said that he knew somebody in the next room that he wanted me to meet. Following Mr. Enck into the room I saw Jim Prentice for the first time. Jim was conversing with another person and using a device that I'd never seen before. After Mr. Enck introduced us to each other he left the room and I asked Jim what the device was called. When Jim said that it was named the ELKOMI T M I told him that I was trying to obtain a communication device for myself he replied, "Yes; I know. I'm your new mentor". I looked bewilldered and he added with a smile, "Whatever that means".

During the next several months Jim and I became good friends. If there was a major difference between Jim and my boyhood friend, John Campbell, it was that John had no speaking difficulty and Jim wasn't able to speak at all. In spite of that difference they were both equally good communicators and teachers. They both had to begin with the presumption that they knew more about the subject they were teaching than their pupils, which in my case, they most certainly did. They came across, however, not as a more intelligent person trying to communicate with a less intelligent person but as one intelligent person conveying information to another intelligent person so that they might be equally informed. In my opinion; this is what separates the real teachers and the real leaders from the rest of the pack. Real teachers instigate the desire to learn within their students and real leaders instigate the desire to act not only because they might think that

it's the right thing to do but often just because followers want to please their leaders.

Jim recommended that I contact Bruce Baker and his staff, the people who were responsible for the software which communication devices use, what was then called The Rehabilitation Institute in Squirrel Hill, for training on communication devices, Temple University, for more intense training on communication devices and The Rehabilitation Institute, for followup training. Whenever I would contact Jim from time to time he would ask me, "Hows' it going" I would then give a progress report to him and we would go on to talk about other matters. He never pressureed me to do anything but for unexplainable reasons I always felt that if I wasn't following his recommendations I had better have a good explaination as to why I wasn't doing so: if not for him then for myself. I feel that Jims' mentoring helped me get to where I am today.

What struck me most about the morning I discovered that Jim suffered a Brain Stem Stroke wasn't what I remember but what I don't remember. I can remember my attendent coming into my bedroom on the morning of September eleventh, two thousand one and telling me that New York had been attacked. Although I felt sad I was able to go through the day with a clear mind. On November twenty-third nineteen sixty three I remember a physical therapist came into our classroom and told us that President Kennedy had been shot. I also remember feeling sad on that day but I didn't have any lapses of memory that day either. On the morning of Friday August third, two thousand seven I had just finished signing in for the Pittsburgh Employment Conference (PEC) when I heard Bob Conti, Bruce Bakers' right hand man, mention to another person that somebody had to be rushed to the hospital. A few minutes later I became aware that the somebody in question was Jim Prentice. I remember the voice conveying the news to me. What I don't remember, however, is whether the voice was a male voice or a female voice. Whether the voice belonged to someone who I knew very well or whether it belonged to someone who I had never met. I just remember that it seemed like a gigantic shroud of sorrow had fallen over the Sheraton Hotel where the conference took place and everybody who participated in the conference. I got through that day and the rest of the conference only by really concentrating on what I was doing. At the end of the conference I had to realize that Jim had more of an impact on my life than I had known and that I really wasn't as unshakable as I once thought that I was.

James William Prentice was born with the ability to barely move under his own power and without the ability to speak. He was also born in nineteen fifty; a time when people with severe physical disabilities were still not thought of as people who would accomplish very much; probably living in an institution most of their lives where they would be cared for by others. With all that going against him it would have been understandable if he wanted to give up on life and just persue the limited pleasures he may have had to enjoy. Jim, however, wanted to make something of himself. The first step in doing that was finding a way to communicate with the people around him. In the nineteen fifties the only Method for people with speaking difficulties to communicate with others was called the letter boards. Those who had some movement in either their hands, arms, legs, feet or head could point to various letters to spell messages. As time passed speech-language pathologist and therapists devised techniques to group these

letters into words phrases and even paragraph to these boards and later punctuation. Even in their most advanced and efficient state these boards were very t e d I o u s to use. Jim took one of these letter boards and utilized it first to acquire an elementary education at a Special Education Center and subsequently a Degree in Business Administration from a community college. Over the years the communication devices Jim possessed became more useful and efficient as assistive technology progressed and new technology enterprises came on the market. Jim ascended from a letter board to an advanced version of that device known as the ELKOMI TM, made by Thorn Automation in the Netherlands and distributed by Prentkie Romich a new electronics company which was establishing itself. Over time Prentkie Romich provided Jim with a Liberator and then a Pathfinder which were both state of the art devices when they debuted.

Potential leaders don't attain success by taking on a project all by themselves. Their success is measured by how much enthusiasm they can instigate in whatever people are around them to assist them in whatever projects they might encounter. In Jims' case the people who surrounded him was his father, mother and two sisters. Together they began a printing business. Jim would solicit potential customers by advertising the printing business on the back of his power chair. He tried and often succeeded in attracting patrons who wanted business cards printed as well as other commodities printed such as wedding invitations or announcements of special events. If he was successful at selling his service Jim would write down what the customer wanted printed into his communication device, take the information home with him and either print the material requested on his copier or whenever there was a complex order telephone the specified data to a printing house for it to do the printing.

One night Jim sold his services to a customer who would change his life considerably and give opportunities to him that he probably never thought he would attain on his own. Attending a public meeting at United Cerebral Palsy Jim met Bruce Baker who, among other professions, was a software specialist working at the time for Westinghouse as a consultant. Westinghouse wanted to know whether any of the products they were developing could serve people with speaking disabilities. They also wanted to know if anybody using a communication device and any products which Westinghouse was developing might be able to accomplish tasks that were assigned to them by management. In other words; they not only wanted a somebody to experiment on they also wanted somebody to experiment on who was pretty bright. When Mr. Baker received the business cards he had ordered from Jim he encouraged Jim to submit his resume to Westinghouse. When Jim did this Westinghouse selected Jims' application from several other augmentative communication device users because of his educational background and his positive experiences within a business environment. Westinghouse didn't give Jim a job because they thought he was a nice man. They gave him a job because they thought he could help them sell their products to people with physical disabilities. Since the problems that people with physical disabilities have are various and sundry with aid to one person being a hindrance to another; developing a product which could serve the disabled population equally ment that Jim had his hands full. Apparently, however, that is what he did.

Being an employee of Westinghouse earned Jim a certain notoriety. In nineteen eighty six Jims' name appeared in the Wall Street Journal within an article titled "The Westinghouse Project" written by Brian Burroughs. Several years ago there was another Pittsburgh Employment Conference. At that conference there was an award ceremony to honor an Office of Rehabilitation conselor, named Gil Selders, who was being presented with a lifetime achievement award. Westinghouse asked Jim to represent the company and to give a speech on Mr. Selders' achievements from Westinghouses' perspectives. When it came to Jims' turn to speak he was introduced as the Westinghouse employee who had just earned his first vacation. From what I've learned in studying Jims' history with Westinghouse I've come to the conclusion that he may have done too good of a job for his own good. He was laid off in nineteen ninety six because Westinghouse claimed that his job had been outsourced. However, another way to look at it is that he accomplished everything Westinghouse had given him to attain and the company simply had no more work for him to do.
I don't think Jim would have retired for quite some time. If he would have been a retiring person he wouldn't have lived the life he lived in the first place. He probably would have gone on to other challenges and conquered those. Unfortunately, he won't have that chance. Jim suffered a Brain Stem Stroke on the morning of Friday, August third and taken to West Penn Hospital. He died nine days later in Forbes Hospice at the age of fifty seven.

There is a saying that goes, "They don't make 'em like they use to". In some cases they are right and in some cases I'm glad that they are right. Polio which afflicted my former boy scout patrol leader and good friend , John Cambell, has all but been eradicated. Birth defects, the primary cause of Cerebral Palsy, which afflicted Jim Prentice and myself is also on the wain. Although I would like to see the lives of people with disabilities improve vastly in the future I would like the idea that there will come a time when there will be no people with disabilities because the cause of the disabilities will have been eliminated. I also feel, however, that if there are not people such as John Campbell and Jim Prentice who don't take risks and hardships upon themselves in order to blaze a trail for their peers society will decline.

Semantic Compaction® Systems, Inc. in conjunction with SHOUT AAC to present the premiere of

FRENCH TWIST

A new ten-minute play by Gregg Mozgala,
Author of "Game Legs," "Spaz!" and "Sex On Wheels"

PERFORMANCE ON AUGUST 6

In **FRENCH TWIST** two friends travel to Europe. When they decide to stop for lunch in a Parisian restaurant they are forced to deal with the rigors of traveling in a foreign country, snooty waiters, language barriers, and a beautiful French woman which all serve to expose fissures in their relationship. The cast includes Kevin Williams as CHRIS, an augmented communicator, and Gregg Mozgala, as JIM, his well meaning but over protective friend. The cast is rounded out by Elizabeth Pegg, as LOUISE, the young attractive French woman, and Cre Engelke as THE WAITER.

SHOUT, a 501(c)3 nonprofit corporation, has as its mission advocacy for employment of people who rely on augmentative communication. As part of its mission, SHOUT has hosted numerous three-day Pittsburgh Employment Conferences for Augmented Communicators (PEC@) in the past 18 years. With hundreds of attendees drawn from four continents, PEC@ is the only conference in the world focused on employment outcomes for people who use augmentative communication.

Gregg Mozgala is an actor and writer based in New York City. He most recently appeared in the North American premiere of Gian Carlo Menotti's, *The Medium* as part of Spoleto Festival USA. He has been in various productions off and off-off Broadway with Rattlestick Playwrights Theater, The LaByrinth Theatre Company, Tamar Rogoff Performance Projects, Theatre Breaking Through Barriers, Foolish Theatre Company, The Brick Theater, The National Theatre Workshop of the Handicapped, Visible Theatre and the Ensemble Studio Theatre. His work with choreographer, Tamar Rogoff has been featured on *CBS Sunday Morning* and *Good Morning America*. His plays have been produced or presented at a variety of venues including, the Kennedy Center for the Performing Arts, Theatre Breaking Through Barriers, Visible Theatre and The Ensemble Studio Theatre. For more information visit www.greggmozgala.com

Living with a Disability: Owning My Own Business; Being an Entrepreneur, Being a Mentor to Other AAC Users

Panel Discussion Participant:

Living With a Disability, Like a Fairytale Book for Children

Luis Ross

Ambassador, Prentke Romich Company
Assistant in the Auditor Department &
Designer of Auditor Department Newsletter
Phoenix, Arizona

To me, my childhood life was like a fairytale book for small children. My name is Luis Ross from Nogales, Arizona but I was born in Mexico, about 5,000 miles south of the border on a small ranch; with Cerebral Palsy because the umbilical cord was wrapped around my neck so I couldn't get oxygen throughout my brain. The kind of cerebral palsy I have is call "athetoid cerebral palsy."

When I was born my wonderful grandfather gave me a nickname; the miracle boy. I don't know why because I was an ugly little boy. My mother and I went to live with my aunt and uncle in Nogales, Mexico when I was two years old. In Mexico, there was nothing for me, like special doctors, so my mother placed me in a good school in Nogales, Arizona.

Every morning a bus would cross the border to pick me up and take me to school. My sweet mother decided to give me up for adoption, but she had very difficult time on deciding to give me up or not. Then she realized it was the best choice that she made for me – to be adopted. But we never stopped seeing each others until this day. I was very lucky; I met a nice American man who adopted me, when I was four year old. The American man was the bus driver. His name is James Ross; he is so loveable, kindly, warm-hearted man and very sweet man. I feel and until now feel very lucky man that he adopted me.

Sometime I ask myself, why he chose me to adopt because there were and still are worse off children than me in Mexico. When I was growing up my father took me to many doctors who told us I would never walk or I would end up in a group home by the age 18 or 20. My father just looked at the doctors, just smiled and told them THANK YOU -- no matter what anybody tells us. During my school years when I was growing up, my father and I had hard times with the public schools; but he never gave up on me to get a good education and to be treated like a regular student. I was not in special education class all the time. I was there just to do my homework and get some help with my writing skills. All of my teachers wanted me to be in a special class or a private school for people like

me. I was in regular classes until I finished high school. I remembered one time, I had a hard vice principal when I entered high school. So, my father, his lawyer, the vice principal, the other principal, and my teachers had a meeting in the beginning of the school year.

My father said, "I want for my son to go to high school here and to be graduated until 21 year old." Well, the vice principal got up from her chair and she started screaming to my father, like your child should be in a private school, we shouldn't allow him to go to school here. So, couple of months went by and one night we got a phone call from the vice principal saying she was real sorry about what happened in the meeting. Do you know why? She had an accident and ended up in the wheelchair.

My school years were okay, but throughout I had kids who would tease me, laugh at me about the way I walked or pushed me until I fell down. Of course, it hurt me but that is life for a lonely person with disabilities. I remember one time, my father and I were walking through the mall, and suddenly I felt down. My father didn't want to help me to get up from the floor. He wanted me to try to get up on my own. I started to cry, yell and kick. We were there about eleven or twenty-one minutes. My father sat down and waited patiently while I got up from the floor, but, of course, he almost got into a fight with people for what he was trying to do for me.

Please, please let tell you something. If my father had helped me back then, I would not have learned how to be independent these days. I had a neat speech-language pathologist when I started school until I finished high school. I think that I had a great childhood. My father was an angel with me and didn't treat me like if I had something the matter with me; he treated me like a regular kid. I have some good days or bad days in my life like people can be mean, treat me like I'm an invisible person. Sometimes they think I have a kind of disease. I've always had people be rude toward me. Please, again I'm not here to bore you with my life. I just want to help you realize that the disabilities people are human beings.

Even to help you guys, we can't become absolutely anything like a normal person, but let me ask you something? What is normal? Everybody here at one point had a broken arm or a broken leg. Just think for a moment, how you would feel and now think about a person having one all his or her life.

I'm one of the ambassador for the Prentke Romich Company, the company who designed my talking machine. I will say more about this kind of machine in the middle of my talk.

Some people say I am an amazingly, focused individual human being. They say that I do not sit back and wait for things to happen. They feel I set high goals and expectations for myself and do not rest until I have reached them. For myself, I don't believe this because I think I'm a regular guy like you. I have a landlady who thinks I'm a sick person or I have a problem with my brain. She gives me a hard time when I need something to be fixed in my apartment. But one time I shocked her with a question that I asked her about my rent. She didn't know to react to the question; she was quiet. I bet, if you see me

walking down your neighborhood, you will think I'm an ill person or something -- you may probably call the police on me. It is okay; I don't blame you, but remember looking from the outside of the person is all different from what they have inside of them. I remember when I went to Wal-mart, because I was looking for some pants. I asked a lady excuse me, do you have some pants in my size, please. I told the size on my Pathfinder and she just looks at me like I was drunk or stupid. She shook her head no and walked away. She was wearing a Wal-mart jacket. I wanted to yell, kick, or tell her off, but I didn't. When I got home, I said bad words in Spanish and English, because I was so upset.

I went to restaurant. I ordered our food to take home, while I was waiting for my food, two boys walked by us several of times, and they started to make fun the way I walk. I got real upset, I was ready to get into a fight with them. Because sometimes, it get tired when people makes fun of people with disabilities. I don't mind if a child comes up to me and questions me about my disability. This is my opinion, but everyone has a different opinion about this question.

I think it was one year ago. I went to Walgreen because I was going to buy an electric razor. I couldn't find them and I asked the sale person, excuse me, "Where are the electric razors and other questions as well?" She said, "Please sir; take your time. I'm here to help you," and it made me feel like a real human being. I went back to tell her thank you for your kindness help and your patience, because most people are not friendly with me or when they look at me, they would away.

I like to watch people when I walk by them; they sometimes get scared of me and move away quickly. Sure it makes me very sad and mad but what could I do about it. I have learned the hard way there are good people and there are some mean people who think I should be in a Group home that I shouldn't living independently.

I do trainings for city employees. This is the way like I like to do this kind of trainings for the city employees, because for you guys to be here, you are helping us by going back to your family or friends tell them that disability people are not different then regular people. I like to challenge myself always, like search new jobs and find ways to improve my independence. So, about three years ago I went to a company with my resume to see if they would hire me for a job. There were two people; one of them was the boss and the other person who would train me if I got hired. They asked some questions. I answered them with my communication device, and suddenly, they started laughing at me because they couldn't believe what kind of things I do in my job. I felt very upset about what just happened.

All of my life until now, people see me from the outside and do not get to know me from the inside. I have a part job with the City Of Phoenix in the Auditor Department for 12 years, with the help of the Clear Path Program. I'm one of many people who successfully found a part-time job. I like working at the Auditor Department, because they don't see me like a person with disabilities, but they see me like a real human being. My jobs in the Auditor Department are designing monthly newsletters for our library, helping out the

auditors with projects in PowerPoint Windows, scanning newspaper articles, and I deliver mail to the co-workers.

I know this is silly, but every time when I go in to work I always get nervous, because I don't want to mess up the work. I feel very lucky to have a good job with great co-workers who have good hearts.

It is funny sometimes; I have a few bosses at the auditor department. Anyway, I have one pretty good lady boss who always has jobs to help her out, and it makes me feel good about myself because many people see from the outside but not her. Sometimes I want to pay her, because she is nice to me. I know most people go to work because it is a job, but for me it is a learning experience every week, and I try to not think about people think of me. I'm also working at the Clear Path Program part time with the help of three auditors and the staffs of Clear Path. I like working at the Clear Path program, because they don't see like I have a disability but like a regular guy.

I sometime thanks God for this wonderful program. Without this program; most people with disabilities would be working at a center or not working at all. At the Clear Path my jobs are searching jobs for the interns or working with PowerPoint for presentations. And sometimes on Fridays afternoon, I help out a 12 years old to learn her pathfinder device.

It is funny, I went in to burger king with my mother and nephews, and I was ordering our food. There was a 11 year old boy beside me. He started to ask me questions about myself; like why are you that way or what happen to your arm. Sometimes I get very nervous when people stair at me and my arm moves a lot. Anyway, his mother told him to be quiet and that I was sick. I wish I have a lot of time to education small children, because they are our future. I have been living on my own for 10 years now, and I decided to move to Phoenix, because there are thousand opportunities for people disabilities. I lived with a roommate for three years. I moved into my own apartment with some help of a program. I have my own apartment, and I feel safe where I'm living at right now.

I could do anything, like: come home in the morning, listen to my radio loud and invite people to sleep over whenever I want to. It is scary sometimes to live on my own plus I'm a worrying person, but I do my best. I have a care provider who comes every morning to help me things like: cooking, grocery, teaching me to how to speaking up for my right, and I don't let people take advantage of me; and with my personnel stuff. Life is not easy.

This machine is called ECO, but I call it my baby, because it goes everywhere with me out in the community. It is funny, when I get on the city bus, and the bus driver would ask me where I'm going and I tell him with my ECO. They would say I like your voice. This machine costs 8 thousand dollars and Medicaid paid for it. The way this machine works is with icons on the overlay. It has pictures and letters that represent a word or a complete sentences. I have had a machine with this language called Minspeak for 19 years. I have gone to conferences to show people how I communication in New Orleans,

Pittsburgh, and different places in California. I have certificate in desktop publishing and I have a degree in general business from Phoenix College. I do presentations for the city employees every month and also for the students at Arizona State University (ASU). My goal in life is to talk with small children; to tell them that if you believe in yourself anything is impossible. Don't let anybody tell you can't do that or it's hard for you; just prove them wrong. My second goal is to open a company where I can design ECO cases and still educate people out in the public about people with disabilities.

And I will give you this advice, treat people like you want to be treat in life. Just put yourself in their shoes for a moment and think how you may feel talking that way. Thank you for your time.

Living with a Disability: Owning My Own Business; Being an Entrepreneur, Being A Mentor to Other AAC Users

Panel Discussion Participant:

Daniel A. Shirey
Natrona Heights, Pennsylvania

My name is Daniel Shirey and I am a disability consultant and an AAC user. I started a company called DAJ Consultants in 2003. What we do as a company is educate the general public and help them understand people who have a disability and the struggles of our every day lives. We do this by giving presentations to college students and anyone else who will have me. We also mentor others who are pursuing a career in a field that specializes in working with people who have a disability.

My AAC device has helped me tremendously with delivering my message. I would not say that I could not do my job without the device, because I believe where there is a will, there is a way, but it would be much more difficult to deliver my message. The device helps me project my voice so others can clearly understand me. Without the device, I am very difficult to understand. If you have not met me before or have never talked to me, it will take you a while to understand me. I do not have the luxury of time when giving presentations. I need people to understand me right away and that is the biggest asset to my AAC device. In a nutshell, this device makes me more marketable.

There are a number of organizations that help entrepreneurs such as myself. The one that I have worked with the most is Working Order, also know as Volunteers of America.

If you have any questions for me, or about my company, please ask. If there is not enough time during the panel session, I will be here for the rest of the day.

Living with a Disability: Owning My Own Business; Being an Entrepreneur, Being a Mentor to Other AAC Users

Panel Discussion Participant:

Robert O'Gurek, A.A.
Schnecksville, Pennsylvania

Last June I opened my own business called Bobby O'Gurek's Web Design & Services. As of right now, I have 19 active web sites for clients. Three clients are local government contracts. The rest of the web sites are for businesses and organizations. When I first started my business, I didn't advertise because I brought on my clients from where I worked at before. I had a lot of work to do with keeping their web site up to date. However, I started my business with a facebook page and it really blossomed. (www.facebook.com/Bobby.OGureks.Web.Design) My business page has 453 fans and it is amazing how social media works to get the word out about what I am working on. You can find my web design business if you search Bobby O'Gurek's Web Design & Services on facebook. You can like the page then if you want. I also have a business e-mail address and a web address for a web site. My web site is currently under construction, however I use my new e-mail address. My business e-mail is WebDesign@BobbyOgurek.com. Feel free to e-mail me any time with questions or if just want to talk.

Web site address: www.bobbyogurek.com (My web site is in the design stage)
Here are some of the web sites I have designed:

- Shake, Rattle, & Soul - www.shakerattlesoul.com (Newest web site)
- Matika For Judge – www.matikaforjudge.com
- Nanovic Law Offices www.nanoviclaw.com
- Towamensing Township - www.towamensingtownship.com
- Borough of Lansford - www.boroughoflansford.com
- Lower Towamensing Township - www.lowertowtwp.com
- Borough of Summit Hill - www.summithillborough.com
- Summit Hill Heritage Center - www.summithillheritagecenter.com
- Summit Hill Fire Company - www.summithillfire.com
- Summit Hill Memorial Day Parade - www.summithillparade.com
- The Winners Forum - www.thewinnersforum.com

I made and handle the following facebook pages:
Diligence Fire Company no.1 of Summit Hill pa
Summit Hill Stay-At-Home Festival
Memorial Day in Summit Hill, Pennsylvania
St. Joseph's Annual Parish Festival

Raising the Bar for Vocational Opportunities & Greetings from the President Elect of USSAAC

Patricia Ourand, M.S., CCC-SLP
President Elect, USSAAC
Baltimore, Maryland

Abstract: Raising the Bar for Vocational Opportunities

The technologies most often discussed for individuals with severe disabilities entering the workforce often refer to AAC technologies. However, this doesn't have to be the case. Today, research is being conducted to investigate technologies (gadgets) that can address and monitor people's needs. So, the question is, what if this "gadget" category of technologies were integrated with mainstream and assistive technologies to increase participation and independence in the work setting (e.g., telecommuting, home-based business, office) for individuals with significant physical and/or intellectual disabilities? While the research being conducted is primarily addressing the aging at home population, the end game is the same for both groups of individuals– to increase or maintain participation and independence in your desired environment. Those stakeholders interested in raising the bar for vocational opportunities for individuals with disabilities may be able to take full advantage of the research investigating the role of new technologies for increasing and maintaining participation and independence.

Paper: Raising the Bar for Vocational Opportunities

Bjelland, Erickson & Lee (2008) report that in the year 2007, an estimated 74.3 percent (plus or minus 0.1 percentage points) of non-institutionalized, men & women, with or without a disability, aged 21 to 64 years, all races, regardless of ethnicity, with all education levels in the United States were employed. The estimated percentage above is based on a sample of 1,692,615 persons who participated in the 2007 American Community Survey (ACS). However, this information must be tempered with information reported by Wagner et al., (2005) noting that individuals with multiple disabilities, including those who use AAC, experience the lowest level of employment of any major disability group.

This information is further supported by an Information Memorandum (IM) dated September 22, 2000, which provided information and guidance to designated State Vocational Rehabilitation (VR) agencies about the need for attention to the provision of VR services to individuals who face Significant Speech and Language Challenges (SSLC)" and was disseminated to multiple agencies, including State Vocational Rehabilitation Agencies (General and Blind); State Rehabilitation Councils; Client

Assistance Programs; Protection And Advocacy Of Individual Rights Programs; Regional Rehabilitation Continuing Education Programs; American Indian Vocational Rehabilitation Programs; and the RSA Senior Management Team. This memorandum was also intended to assist State VR agencies in the determination of how well they are serving this population and to explore what corrective actions can be taken if warranted.

This IM states that AAC "is a rapidly developing discipline. In particular, over the past decade significant advances in assessment and therapy, combined with current technology, have dramatically improved the potential for positive outcomes for individuals with severe speech and language impairments. Today, ACC systems and technology effectively serve both children and adults with a wide range of physical and cognitive impairments". The IM notes further, "Despite these advances, however, the number of individuals with significant speech and language challenges who attain appropriate and successful employment outcomes remains relatively small". A more recent acknowledgement of this problem for one subset of individuals with disabilities, specifically Autism, was discussed in the Baltimore Sun on February 15, 2011. It was noted that the National Institutes of Health have begun to call attention to the need for more services and research into the needs of individuals as they transition and age into adulthood and the vocational world.

So, what do we do? Raise the proverbial bar for vocational opportunities for individuals with disabilities in general, and more specifically for those individuals who utilize technologies for writing, speaking and environmental control. The new is not all bad. Blackstone et. al., (2007); Bryen & Moulton (1998) have reported that individuals who utilize technologies are experiencing new expectations for adulthood. Atanasoff, McNaughton, Wolfe, & Light (1998); Bryen, Slesaransky, & Baker, (1995); Bryen, Potts, & Carey (2007); Carey, Potts, Bryen, & Shankar (2004); Isakson, Burgstahler, & Arnold (2006); McNaughton, Light, & Arnold (2002); (Davis, 2005) and Chung (2004) among others have recognized that over the recent decades, the availability of appropriate technologies has supported desired outcomes for individuals (e.g., college and university settings; employment and independent living).

The technologies discussed up to this point have generally referred to AAC technologies. An article in the Chicago Tribune on July 19, 2010 written by Steve Johnson stated "within a decade or two, researchers predict, consumer gadgets will be functioning as hyper-attentive butlers, anticipating and fulfilling people's needs without having to be told. Life not only would be more convenient, it even might last longer: Devices could monitor people's health and step in when needed to help them get better". Or, what if this "gadget" category of technologies was able to be integrated with mainstream and assistive technologies to increase participation and independence in the work setting (e.g., telecommuting, home-based business, office) for individuals with significant physical and/or intellectual disabilities? The Los Angeles Times published an article by Walter Hamilton on June 17, 2011 where he proffered the belief that "games, monitors and robots are among the tools being tested to help aging people live in their homes as long as possible, while lowering risks to their health and safety". While the populations being discussed may be different the end game is the same – to increase or maintain

participation and independence in your desired environment. Those stakeholders interested in raising the bar for vocational opportunities for individuals with disabilities may be able to take full advantage of the research that is currently being conducted by the Oregon Center for Aging & Technology with partial funding from Intel Corporation, along with the many other researchers investigating the role of new technologies for increasing and maintaining participation and independence.

Examples of potential workplace technology-based enhancers could include:

- Motion detection of movement patterns and timelines
- Audio sensors to monitor sounds that might suggest weakness or disorientation
- Skype-like video monitors to check on workers pace and locales
- Pill boxes to track medication administration
- Motion sensors along hallways and ceiling to record gait and walking speeds
- Monitors on doors to track when a person arrives and leaves

These are but a few of the new technologies, or should we say new uses of technology that will likely enable more individuals to work in general, to work at a faster pace, to work with increased responsibilities and the list continues.

Case Study:
Alex is a rehabilitation engineers working with a high level spinal cord injury. He has designed and patented a new product, but his "day job" prevents him from actually starting a business to market and ship the product. Joshua is a young man recently graduated from college following a stroke during a surgery to repair a shunt due to his Spina Bifida. He experiences significant short term memory deficits, but utilizes technologies to organize and remind him or timelines and responsibilities. Joe is a 20 year old young man about to transition from high school to the workplace. While he functions with severe Autism, he does bring many skills (e.g., visual matching, following verbal and visual directions) to the workplace, as does Joe who is an 18 year old young man with severe Autism aging out of the educational system in 4 years.

These last three young men plan to buy a home, with the support of their parents that has the room downstairs for an office and small distribution center. They propose to live upstairs and work downstairs with the support of many of the "gadgets" described above, as well as some other modifications and supports.

Finding a Job

Kathryn May, B.S., ATP
Texas TERA (Technology Empowerment Resources and Advocacy)
Round Rock, Texas

Good afternoon everyone, I hope that everyone is enjoying the conference. When Bob Canti asked me to give a presentation on finding a job, it caught me off guard. I guess he asked me sometime around February. Ironically, four months previously, around October I had been told that my job position with the school district was going to be cut at the end of the school year, June of this year. I had been working for the school district for about five years as an Assistive Technology Teachers Assistant. My role was to support students who used a communication device and staff supports. I would travel around to Austin schools providing assistance, technical support, and implantation methods to students and staff needing help with their communication devices.

So Bob had hit the hammer right on the nail, how was I going to find a job? As we know, the job market is terrible and millions had been laid off. In some ways, knowing that I have to find a new job by June was a relief for me. Even though I love working with the students and staff, it was sort of getting boring for me. It gave me a push. It was like something above was pushing me off the cliff and saying get on with your life. So after the shock wore off, I started, once again, networking through people that were apart of my life. This was something I was very familiar with because I have had two other jobs that became realistic because of networking. They always say that it's not what you know, it's who you know. Well hopefully I know something.

Luckily after working ten plus years in the Assistive Technology field, my networking had grown drastically. I think I knew every speech therapists, physical therapists, and occupational therapists in my school district. Many of the connections were very disappointed that I was leaving the school district because they had valued my expertise. They all started to search for jobs for me.

Eventually, I found myself contacting people that I had known since elementary school. I have been very fortunate to have grown up with a family with high expectations. My mom, the engine of my train, never settled for less when it came to my education or whatever it was. It was funny to me when I worked for the school district and we had to deal with "those" pesky parents who just wouldn't leave the district alone until they got what they wanted for their child. I was then on the other side of the fence! Although, I received such gratitude knowing that I could give back what had been given to me by the finest and generous people in my life.

This last Spring, in mist of dealing with other life changes, I had to spend time thinking about who I could network with to seek employment. It wasn't easy as I knew the economy had taken a turn for the worst. I had to market myself as a high skilled assistive

technology professional. In the assistive technology community, state and national, I had climbed the latter and was no longer known as someone who used augmentive communication. I am seen as the professional assistive technology person that thought and supported the newbies entering into the glorious world of AAC.

I knew I could be a private consultant for school districts but I also needed something more secure. One evening, I had a girl's night in with a dear friend of mine, Tracy Custer, who is a regional consultant for the Prentke Romich Company in Texas. Tracy and I first met when I was selected to beta testers for the Liberator, a communication device, which many of us used in the old days. At age seventeen, a sophomore in high school, beta testing was an amazing experience for me. I worked closely with the head of Prentke Romich research and development, Dave Hershburgher, who came down from Wooster, Ohio to meet with me for afternoon to give a short overview of the Liberator. One day I will never forget. Dave went back to Wooster to see his one week son and I worked once a week with another Prentke Romich Company regional consultant, Joy Zabala, a dynamic person. Basically, Dave left me with the job of making the Liberator crash and give suggestions on how to make the device a better product for the end consumer.

I spoke with Dave a few times a week because I became a pro at making the Liberator crash. After we got all the bugs out and Prentke Romich Company was going to make the Liberator's final reveal at national conference, Closing The Gap, Dave asked me if I would present with him about our beta testing experiences which we had a lot of. I was honored to have this opportunity. I had no idea the doors that would become open for me in future.

Or, maybe I did? Like I mentioned before, I was in high school during my beta testing days, and was preparing to go off to college. I realized the importance of going to college and receiving my degree. I also started to think about where or who I was going to work for after I earned my degree. So sometime around the end of my beta testing with the Liberator, Dave Hurshburgher and I were talking, and I said to him, "So Dave, will you hire me after I receive my college degree?" He sort of giggled while I kept a straight face. Then he realized that I was serious and he promised me job after college.

Time pasted, I graduated from college with a degree in Special Education and somewhere in my career I became an Assistive Technology Professional certified through RESNA. After college it took me about a year of major networking to find a full time job. During this year, I did a couple of contract jobs to get some real work experience. I finally received an e-mail from a woman who worked for Advocacy Incorporated, which was one of my networking people. She told me about an assistive Technology Specialist position at the Cerebral Palsy Association which I was hired for soon after applying. I worked for this association for two and a half years and then I was offered another job with an outreach program. Then went on and did five years with the school district in the Assistive Technology Program.

So not only did I have a college degree, I had at least ten years of experience in the assistive technology field. When I heard through the grapes fine, that Dave Hurshburgh, who formed a sister company to Prentke Romich, was looking to hire a Field Tech in Texas for his company I immediately remembered Dave's promise. It was kind of miracle that the stars and moon had a lined so perfectly. I emailed him to see what was up and was it true that Saltillo was searching for a Rep in Texas. He emailed back and indeed they were. I knew the Saltillo products because I supported several students that were proficiently using them.

Dave told me that I would have to be interviewed by one of the head field techs and him. He actually sent the head field tech to shadow me during my work day. I was put to the test to show what I could do. I absolutely loved being interviewed this way because I could show someone who didn't know me, who I was and how I worked. The day went great and the three of us had a skpe interview the next week. I am now a Saltillo Field Tech for Texas.

Currently, I work about 30 hours a week for Saltillo. Plus I am a paid Executive Director of a non profit organization, Texas TERA, a center which lets people with disabilities try out assistive technology. Texas TERA was honored to receive a grant from the Christopher Reeves Foundation last summer. This grant has really allowed Texas TERA to expand and serve consumers, which is very exciting.

So while millions are without jobs, I have managed to work a 56 hours work week. The nice part about it is that I can set my own schedule. Not to say I don't have to get up early, but I have flexibility, which is really awesome.

In closing, it is my hope that the economy gets better and people are able to find jobs by networking people in their circle.

Jumping Over Hurdles to Maintain a Job

Gus Estrella, B.A.
Former Policy Analyst
United Cerebral Palsy of America
Washington, DC

Writer
Tuscon, Arizona

My real task is to talk about how to maintain a job and managed the personal care assistants that made sure I was well fed and dress for my busy day. And at the same time, I had to make sure I had something that resembles a social life. Now in order to maintain a job, you must first have a job. I'll briefly go in to what it takes to find a job, and most likely, I'm going to state the obvious. Nevertheless, at the top of the list is the ability to communicate. It doesn't matter if you are the smartest person in the world, unless you have good communication skills, you will have a difficult time finding a job. This is especially true for people who use AAC, as you will see that it was a crucial skill in my career. I also think personal appearance, attitude, and a solid education are all contributing factors in landing a job. Appearance is fairly easy, dress for the part. Don't go in for the interview wearing jeans and a T-shirt from the neighborhood bar, for an office job. At the same time, don't wear a three piece suit for a position that would have you cleaning toilets at McDonalds. Now attitude is not so easy. In my experience, individuals that are lay back but have a little assertiveness in their mannerism go a lot farther in life, than those who think the world owes them and figures people around them need to worship the ground they walk on. In my life, education has paid a major factor in my career and in a few minutes, you will see how. But first, I will say this about education. Like it or not, a person starts to be educated at a young age by their parents and family members. Then comes the educational system, which could last a lifetime, or it feel like it. I'm figuring a typical person will be in school, preschool through a minimum of a bachelor's degree, a minimum of twenty years. With keeping this in mind, I'll go into how my career started and how my family and educational experience influenced my ability to finding a job and my attitude towards maintaining a job.

Out and About: Using a Communication Aid at a 7-11, at an Emergency Room, and on a Date

Bac Shelton, BFA
Ambassador and Consultant, Prentke Romich Company
Dallas, Texas

My name is Bac Shelton from Ocean Springs, Mississippi. I live in Murphy, Texas, outside of Dallas. 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 across the country like schools and special events to talk to people about my experiences using a communication device. I usually work with one of the PRC regional consultants in the conferences or with John Halloran from Arkansas. John is retired from PRC, but he developed a training for a non verbal autistic children by

using a communication device. My job is to make fun of him by how slow he is bringing up his power point or making jokes about him.

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.

At Mississippi State University, AAC people can be accepted. So, they have a support system at Student Support Service where they can get help with their college curriculum. The service provide them a place where they can take their exams; an attendance, a person who is like a care taker; a place where they can study; and if the AAC user is in the wheelchair and can not get into the classroom, then it is someone at the service responsibility to ask the professor ahead of time to move the classroom to somewhere else The professors at the university now realized that they have to be patience if they have an AAC student. They have to send the exams over to the Student Support Service office. The AAC student is responsible for the exam like to write their names onto the 'time test'.

The MSU also provide a shuttle from campus to town for the disabled students. If disabled students want somewhere like to Wal-Mart or to the movie, their shuttle can help them to become more independent. I have ridden the shuttle from campus to town when I was a student. It was very nice. I highly recommend to my other peers to ride it. It is for free.

As I mentioned about living in Murphy, Texas, I live with my girlfriend and her family. My girlfriend name is Shannon Pedigo. She is 30 years old hot lady, has CP, uses a power chair, and the 'My Toby', the eye gaze communication device. Some of you are wondering about how did we meet, right? Well, Shannon was using the Pathfinder, the PRC old communication device. Carla Aubrey, PRC consultant in Dallas, hooked us up about three years ago where I was living in Little Rock, Arkansas. Shannon & I have been together ever since then.

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.

European Examples of the Participation by People with Disabilities in Employment and Political Life

Søren Vintergaard
Speech and language therapist
Kommunikationscentret
Copenhagen Denmark

Geography
Location: Northern Europe, bordering the Baltic Sea and the North Sea, on a peninsula north of Germany (Jutland); also includes several major islands (Sjaelland, Fyn, and Bornholm)
Area: total: 43,094 sq km
Area - comparative: slightly less than twice the size of Massachusetts
Population: 5,529,888 (July 2011 EST.) Country comparison to the world: 111
Major cities - population: COPENHAGEN (capital) 1.174 million (2009)

Government

Government type: constitutional monarchy
The government is a Liberal – Conservative government with the support of the most right wing party (Danish People's Party).

Economy - overview:

This thoroughly modern market economy features a high-tech agricultural sector, state-of-the-art industry with world-leading firms in pharmaceuticals, maritime shipping and renewable energy, and a high dependence on foreign trade. Danes enjoy among the highest standards of living in the world and the Danish economy is characterized by extensive government welfare measures and an equitable distribution of income
Labor force: 2.82 million (2010 EST.) Country comparison to the world: 106
Unemployment rate: 4.2% (8%) (2010 EST.)

Source The World Factbook (The Central Intelligence Agency 5th of June 2011)

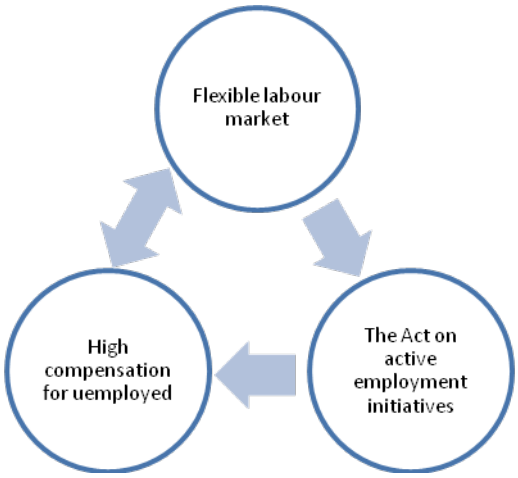
For many years The Danish people have had the most extensive welfare system in the world. Danish citizens pay nearly 50% income tax, which allows its citizens to enjoy a high quality of life, free education, healthcare and unemployment benefits The group of people with working difficulties is around 20% of the working population

 ©SHOUT 2011

The Labour Marked

Flexicurity

Flexicurity" is a term used to describe the special Danish three-sided mix of (1) flexibility of the labor market combined with (2) social security and (3) an active labor market policy with rights and obligations for the unemployed. The actual word is a contraction of flexibility and security. The system is also sometimes described as "a golden triangle".
One side of the triangle consists of flexible rules for hiring and dismissing.



The second side of the of the triangle consists of security for the wage earners in the form of a guarantee for a legally specified payment of a relatively high level if you become unemployed - regardless of your spouse's income. (80%. of minimum wage)
The system builds on an effective labor market system that offers guidance, a job or education to all unemployed – and this active labor market policy makes up the third side of the flexicurity triangle.
http://uk.bm.dk/Themes/The%20Danish%20Labour%20Market/Flexicurity.aspx

Legislation

The underlying principle that guides the legislation in the National Labor Market Authority's area is that active efforts lead to jobs.

The major of our legislation aims to increase the supply of labor.

The main aim of our legislation is to help recipients of daily benefits and unemployment benefits into employment as fast and effectively as possible so they can support themselves and their families. *The legislation also covers people who have a limited ability to work and therefore need special help to obtain and perform a job.*
http://www.ams.dk/Ams/English/Legislation.aspx

The responsibility for employability enhancement measures

The primary objective of the employment enhancement measures is to increase the supply of labor in Denmark. One way to do this is to help people move from public benefits to jobs.

We work towards this objective at three levels: local, regional and national.
Locally:, 91 job centers are responsible for contact with citizens who are unemployed and enterprises which need workers.. The job centers are responsible for all unemployed people and for recipients of sickness benefits.
Regionally :Denmark has four employment regions. The regions support the job centers and ensure they perform well

Nationally: The National Labor Market Authority and the Ministry of Employment have the overall responsibility for the labor market.
http://www.ams.dk/Ams/English/The-responsibility.aspx

Unemployment insurance in Denmark

Unemployment insurance is a voluntary scheme administered by the unemployment insurance funds. Unemployment benefits are, however, largely financed by the State.
If you are a member of an unemployment insurance fund and become unemployed, you must register as unemployed at the Public Employment Service on your first day.
In case you become unemployed and are not a member of an unemployment fund, you may be entitled to receive social benefits.
http://uk.bm.dk/Themes/The%20Danish%20Labour%20Market/Unemployment%20insurance%20in%20Denmark.aspx

The Act on active employment initiatives

The active employment policy aims at contributing to ensuring a well-functioning labor market. This takes place in the form of a number of measures in relation to both unemployed and employed persons who are looking for a job or wishing to undergo training or education. And it takes place in the form of measures targeted upon both private and public enterprises.
The active labor market policy has four overall objectives:

- To assist job seekers in finding a job.
- To offer services to private and public employers who are looking for labor or wish to retain their workforce
- To help persons who are receiving social assistance or start helping to find a job quickly so that they will be able to support themselves and their families
- To help persons who due to reduced working capacity have a special need for assistance in finding a job

The employment measures apply to all unemployed persons irrespective of whether they are receiving unemployment benefits, social assistance, start helping or sickness benefits. The emphasis is on making work pay. *And on ensuring that all unemployed persons are actually available for work. All unemployed persons have a right and duty to receive an activation offer.*
http://uk.bm.dk/Themes/The%20Danish%20Labour%20Market/Active%20labour%20market%20policy.aspx

Accessibility in the labor market

The three most important ways to make work accessible

1.Assistive devices and special designed workplace.

A person with a disability may be granted aids, which can compensate for the disability, he or she has. The assistive devices can be both tools and small workplace layouts.

2. Personal assistance in occupations.
A personal assistant to assist in the job that the person with the disability / impairment itself cannot do. It may be about to pick up and return, take the heavy lifting, reading aloud, acting as secretary, interpreters for deaf people drive in work situations, etc.

Provided personal assistance to unemployed, employed and self employed persons who, because of a permanent and substantial physical or mental disabilities need personal assistance to carry out specific parts of the daily workload.
Accurate Cutting Costs per year 10 -13.000 $

3. Flex-job
Flex-job is a scheme for people who have a significant and lasting reduction in working capacity, and if you cannot gain or retain employment under normal conditions in the labor market.
The job center which will determine whether you have a significant and lasting reduction in working capacity, and therefore whether you are eligible to flex-job.

Working Conditions as flex staff set as a starting point for collective bargaining in recruitment, including social chapters in collective agreements.
Limitations for work described in the appointment and duties performed with consideration for these.

The flex-jobs are subsidized by a permanent wage subvention and may be in both the private and the public sector. Due to the reduced working ability of the target group, the numbers of hours and/or task assignments are reduced according to a specific agreement between the employer, the flex-jobber and the local municipality (the latter being responsible for administering the scheme). The municipal authorities reimburse the employer in the form of a wage subsidy corresponding to the reduction of the working ability of the individual (2/3 or 1/2 of the wages), while the person in the flex-jobs receive the full normal wage irrespective of weekly working hours.
Accurate Cutting Costs per year Price 25 -27.000 $.

Extended version
http://dl.dropbox.com/u/21051790/Denmark%20employment.docx

European Examples of the Participation by People with Disabilities in Employment and Political Life

Cristina Larraz
Speech-Language Pathologist
Centro de Referencia Estatal de Autonomía Personal y Ayudas Técnicas
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Barcelona, Spain (Catalonia)

BACKGROUND

Spain´s recent history starts when after almost 40 years of dictatorship there was a transition to Democracy and our last Constitution is created 1978. We are 46,8 million inhabitants, 3,8 millions are persons with functional diversity. We have 17 Communities with big independence in regulation.

The Constitution is our initial point on how recognition and participation of diverse people in public and political life has increased along the last 40 years. Rights as the following are present in the constitution:

"All Spanish people are equal before the law, without any discrimination on grounds of birth, race, sex, religion, or any other condition or personal or social circumstance."

"All persons have the right to work, to free choice of profession or trade, to advancement through work, and to an income, sufficient to meet their needs and those of their family, with no discrimination whatsoever on grounds of birth, race, sex, religion, or any other condition or personal or social circumstance"

In connection with the fight against discrimination and for equality real and effective of all people, it is particularly relevant the **Convention on the rights of persons with disabilities** of the Organization of the United Nations, approoved on December 13th, 2006. The European Council requested the Commission and Member States to continue the process of signature, conclusion and ratification of the United Nations Convention on the Rights of Persons with Disabilities as a fundamental step for the promotion, protection and full realization of human rights and fundamental freedoms.
In full agreement with the European drive, Spain deposited the ratification on December 3, 2007,

We should also be referred to:

- The **European Action Plan on Disability 2004-2010**, which highlights three operational objectives: full implementation of Directive 2000/78/EC on equal treatment in employment, properly integrating disability issues in Community policies, and improving accessibility for all,

- The Commission Communication on the situation of persons with disabilities in the EU: **European Action Plan 2008-2009.** It reflects the European commitment to ensure that people with disabilities are treated as citizens and that active socio-economic actors contribute to build a sustainable and cohesive Europe offering equal opportunity for all.

Coming back to Spain, during the last legislature, a battery of far-reaching **laws and rules** have been passed. They seek to improve living conditions and effective social integration of people with disabilities in our country in relation to three main areas:
1.- Personal autonomy and care of dependent people with disabilities;
2.- The effective implementation of universal accessibility;

3.- Employment for people with disabilities:

Apart from these new rules, we must be refer to the adoption in **2006 of the Plan of Action for women with disabilities**, including a specific area in order to adapt employment policies to avoid the so-called double discrimination.

CURRENT SITUATION

The social integration of people with disabilities through employment had been addressed in the past through the adoption of specific measures adopted in many occasions, through various laws on fiscal, administrative and social order, and through employment schemes for people with disabilities, characterized by a short-term effect and no projection with concrete steps.

We must overcome both dynamics and adopt a new methodology that allows us to have a clear overview of where we came from and where we want to go. In this vein we should adopt a global strategy Action for Employment of Persons with Disabilities which aims to lay the groundwork for quality employment for diverse people who are entitled to an accessible work, developed in conditions of safety and health, a job that allows the reconciliation of work and family, a job where social dialogue play its usual role in labor relations.

Therefore, it is essential that the Strategy is based on a process of consultation and social dialogue with employers' organizations and unions and associations representing the disability sector, as well as the policies developed in the future. The Autonomous Communities have been made partakers of the work on the design of this strategy.

The very last Royal Decree concerning people with diverse functionality is about Participation of people with disabilities in Public and Political Life.

Greetings from ISAAC International Leadership

Franklin Smith, MBA, CMC
Executive Director, ISAAC
Toronto, Ontario

Faye Warren, B.A.
Executive Board Member, ISAAC
Ocoee, Florida

On behalf of ISAAC International, we would like to thank Bob Conti, Jennifer Lowe, and the entire SHOUT Board of Directors for inviting us to be on the agenda at this year's Pittsburgh Employment Conference, and for making us both feel so welcome.

Thinking about the theme of this event, "Focus on Jobs," it occurs to us that although this conference is about the employment of people who use AAC, it is a reality that both individuals and organizations have a job to do. In both cases, we spend a considerable amount of effort defining the job that we are best suited for. And when we identify that job, we strive to do our best to fulfill the expectations of those to whom we are responsible. All of our skills and abilities, our backgrounds and our personalities, come into focus. We are pleased to have had the opportunity of giving you a brief overview of our organization and the job that we do.

Next year, 2012, is going to be a very special year for ISAAC. Having our 15th Biennial Conference hosted in Pittsburgh (July 28th through August 2nd, 2012) will be tremendously exciting, not only because it will give us an opportunity to show off Pittsburgh to the entire ISAAC world, but because we get to showcase how different organizations and people can come together for a common cause. That is what ISAAC is all about. Having the involvement of SHOUT and PEC as part of our Conference Coordinating Committee, along with our other partners, means that we get the opportunity of "**living with**" the concept of bringing groups and organizations together for a common cause, not only speaking about it!

We hope that everyone attending PEC this year will have a fulfilling and meaningful conference, and we look forward to seeing everyone in attendance for ISAAC's 15th Biennial Conference in 2012.

PEC@2011
Employment: Focus on Jobs

Platform Presentations

Day 3

Getting to the point of where I am in my life was not an easy journey. I lived in a group home for six years. A home in which I felt I did not belong. I was much higher functioning than… most of the staff. I wanted more out of my life… People at my group home used to tell me "you will never make it on your own." … I found it ironic that the very people who were suppose to be supporting me and looking out for my best interest were the very people who were trying to hold me back… Within one year of living in my own apartment, I was also running a small vending business, and managing my own staff, to assist me with everyday living skills, such as cooking, cleaning, and driving… The next goal in my life is to one day have a strong enough business to support myself fully, and not be forced to live under the restrictions of state aid, and live as independent as humanly possible.

("How AAC Helps in Achieving Independence" -- Todd Hutchison)

How AAC Helps in Achieving Independence

Todd Hutchison
Hutch Snack & Co./Hutch Gift Shop
www.hutch-gift-shop.com
Buffalo, New York

My story

My name is Todd Hutchinson and I have a disorder called Cerebral Palsy. Many people assume that I am slow, or have a low IQ because of my physical disability. People assume that because I am in a wheelchair and don't speak the same as everyone else that I am not capable of fully understanding everything that is going on around me. In reality my brain functions just as yours would. It can be frustrating at times to have people think less of you, but at the same time I figure I might as well take advantage of the aspect. I find people can be more sympathetic towards people with a disability, so if I am going to be labeled, I might as well take full advantage while I can. I use an AAC Device, which assists me with communication. From the ages 4-16 I used a board with pictures. I had learned from the pictures how to express what I was feeling. It would get very frustrating when new people could not understand what I was trying to say, or express the point that I was trying to get across. Which in turn would aggravate me. Can you imagine what it was like trying to pick up girls? In 1984 my computer teacher had introduced me to an Apple System Computer. Within two months I learned everything about the computer. My own teacher even began coming to me, asking me questions on how to use the computer. She was amazed that I had picked up all of this information within such a short amount of time. My speech teacher thought of an idea and 2 years later she had given me a Touch Talker to try out. I thought this was a joke and that it wasn't going to assist me because I could not remember the program because all their pictures were totally different. To resolve the issue we cleared out the memory from the device, then my teacher and I put a program together with the pictures that I was familiar with and could associate with words, and phrases, so that people could understand what I was trying to say.

When first putting this program together, my teacher thought that I was trying to put the pictures to words, but she listened to what I was trying to do and did not judge what she thought the outcome would be. When the program was complete the AAC Device was ready to go. I could not believe I was actually going to be able to talk. I was in awe. My speech teacher started to cry. In the passing years, I have been through two AAC Devices that kept advancing with the rate of technology. In the last four years I have upgraded to a Pathfinder. The Pathfinder is a portable device and can be used in dark settings because it lights up in the same fashion that a cell phone would. This was more suitable for my lifestyle, due to the fact that I like to go out to local bars to see live bands, meet new people, and hit on girls. Just recently I have upgraded to a far more advanced communication device called the Eco2. This has been my connection to the social world.

Not only does it help me to speak to someone while I am out in society, but now I can connect to the internet from almost anywhere, text people from my device while connected to a cell phone via bluetooth, and have access to a computer, with a Windows operating system. This gives me the liberty to listen to audiobooks, music, and also watch movies right from my communication device.

Getting to the point of where I am in my life, was not an easy journey. I lived in a group home for six years. A home in which I felt I did not belong. I was much higher functioning then my peers, and sadly most of the staff. I wanted more out of my life, and felt I had the means to accomplish my goals. I heard rumors of a program that would give me the opportunity that I was looking for. A program that would enable to me live on my own. I began planning budget, and was soon able to enroll in the program. People at my group home used to tell me "you will never make it on your own." Their negativity only inspired me to achieve my goals. I found it ironic that the very people who were suppose to be supporting me and looking out for my best interest were the very people who were trying to hold me back. I had to live in an assisted living facility for a weekend to prove to them that I was capable of living on my own. I proved everyone wrong. Not only did it feel great to accomplish such an "impossible" task, but it felt even better to show all of the negative nay-sayers that I was indeed stronger then I looked. Within one year of living in my own apartment, I was also running a small vending business, and managing my own staff, to assist me with everyday living skills, such as cooking, cleaning, and driving. I may have forgotten to mention the fact that I also purchased my own vehicle to assist me in everyday life. This was beneficial because now I would not need to rely on staff having an appropriate vehicle to support my needs. I have now been living on my own for the past 5 years. I am living proof of what can be accomplished if you want something bad enough out of life. The next goal in my life is to one day have a strong enough business to support myself fully, and not be forced to live under the restrictions of state aid, and live as independent as humanly possible.

Hutch Snack Co. & Hutch Gift Shop

About Todd and his business endeavors

In 2004, Todd was searching for a business opportunity when the idea was presented to him, that he might be successful in starting up his own snack business. He eagerly pursued the idea and a short while later, he opened up his first location of "Hutch Snacks" at an Elma facility and soon a second at 180 Oak street in Buffalo. The business has been a very good match for Todd's entrepreneurial spirit and financial astuteness. He has enjoyed the challenges associated with small business ownership as well as its successes, and looks forward to working with you in the future!

Todd's secondary business, Hutch's Gift Shop (www.hutch-gift-shop.com) and most recent endeavor was begun in 2010. He is the administrator of his own website and handles all transactions from the comfort of his business office at home. He is striving to achieve financial success with both businesses in order to become more financially independent, with the future goal of relinquishing his reliance upon state aid for his living

expenses. Please feel free to see me for a business card, to be able to contact me with any wants, or needs.

A Little Laughter Along the Way Helps

Paul Pecunas
Erie, Pennsylvania

Hey people. It's been awhile since I did a presentation. And I'm out of the loop of the AAC community. When Bruce asked me to come and speak at the PEC conference, I was honored. On the other hand, everyone knows whenever Bruce, Barry or Bob asks you to speak at a Pittsburgh Employment Conference, you better clear your calendar. Not many of you know this, but there is an AAC mob. Bruce is the Godfather. The prominent speakers around the world who do presentations are hit men. If you say no to Bruce, they take your device away. So that's why I'm here, but Bobby, come on, Sunday morning 9 am. I know I haven't been around in years, but do you really hate me that much.

I haven't done any comedy acts in years, but I still got it.

It's like riding a bike. Well, so I've heard.

When I was growing up you know how we are influenced by what our family and society says. My sister called me conceded once, because I said something positive about myself. Ever since then up until recently, I kept quiet thinking -- if I tell people I'm funny, or I have a lot to give. I was afraid how people would think of me. In the past month, I came to realize that it doesn't matter what people think. I realize, in my old age, that I am a good person.

I gotta tell yuh that I love my ECO. It's a chick magnet. Whoever's idea it was to put Windows XP on a communication device was a genius! --- especially for a comedian. The problem is I have to stop, turn my ECO on and say what I have to say. So, I leave my ECO on and made an activity row full of sounds.

Most of the times when I roll I like listening to music. I have wireless internet. I listen to the 80's music. When I like a song, I turn it up. Most people dance when I'm passing by so I would do a 360 and leave.

People love to stair at me, because <I'm too sexy>

So I want to do this.

Hey Todd, give me a look. <If you want my body, and you think I'm sexy come on sugar let me know.>

The problem is. Well two things, first I have to be consciously aware Todd is watching.

 ©SHOUT 2011

My wheelchair works from the back of my head. To keep my chair from not moving and going to stand by mode I have to keep my head still 5 seconds. 1. 2. 3. 4. 5.

<If you want my body and you think I'm sexy come on sugar let me know.>

My Experience in Schools

Victor Valentic
Hamilton, Ontario

Bob and Bruce, thank you for letting me speak to this conference today. I am here to tell you about what my experience has been with speaking to children and adults in the school and college levels. I will also tell you about how I help the students from McMaster University's occupational therapist and physical therapist programs.

About five years ago, when I was watching Little People, Big World, and Matt Roloff was speaking to different schools across the United States and I thought that I could do this in Hamilton, Ontario. However, I had no idea where I could start speaking to different schools. One day in February, a teacher from a high school contacted me to speak at this school. I decided that I should tell this class all about my life story. My father drove me to the school because this school was in the countryside. I had no idea what the students would think about my speech. However, I loved the feeling of how these students loved my speech. They asked me a lot of different and unique questions. I began wondering how I could speak to more of Hamilton's schools.

There are six schools in my neighbourhood. They are two public schools, three Catholic schools, and a Catholic high school. I decided that I should go to one of the Catholic schools and introduce myself to the principal. on the next day, this school's principal wanted me to speak to the whole school. I was totally surprised about this school's principal wanting me to speak to the whole school because when I used to live with my parents, I had watched this school being built. I used the speech which I gave to the class one month earlier. However, I felt that the whole school was too much at once to hear my speech because there were about 400 students and I couldn't see the students' eyes in the back of the gym.

The principal was very impressed with my speech so she sent an email to the superintendent of special education for this school board. She also told me that I should make an appointment to see this superintendent. I had made an appointment to see the superintendent and the superintendent loved the idea of me giving speeches to the schools around Hamilton.

In September after seeing the superintendent, I visited my local neighbourhood school which is five minutes away from my townhouse and introduced myself to the school's principal. The school's principal was interested in having me speak to her school. However, I suggested that it would be better if I spoke to individual grades in a classroom. She agreed that I should speak to individual grades in a classroom. I gave the same speech that I had given to the two schools in my past two speaking events. When I was done speaking to the whole school, I didn't realize how much the children in my neighbourhood were influenced by my speech until I was riding my scooter around the

neighborhood the next summer. I will tell you my observation about this at the end of my presentation.

My presentations are for grade one and up only because the children are more mature at these grade levels. I have found that the children in kindergarten are still too young for this type of presentation. I went back to the second school and asked the principal if I could speak to the school once again. The principal agreed that I could speak to this school; however, she wanted me to speak to one individual class. It was fine by me but something was really bothering me with this because speaking to an individual class was a waste of my time and the message in my speech wouldn't get to the whole school.

Last month, I had a chance to speak to a camp at Mohawk College. This was the Junior Leaders Camp. This was my third time speaking to this camp over a four year period. When I arrived at the classroom, I needed to go to the washroom and while I was going to the washroom, I saw this camp passing me. I thought that it was a little bit strange to have only four teenagers in this camp. In my past, I've spoken to a group of a minimum of fifteen children anywhere. I was surprised that there were only four teenagers in this camp. But I loved speaking to these teenagers because I loved how personal they were with me. I also appreciated how inquisitive they were after their counselor started asking me questions. I also taught their counselor about Cerebral Palsy because she has a second cousin who has CP. I also let their counselor try accessing a word on my eco. This was my first time ever letting a person out of my circle of friends or family members touch my eco. When I was attending Mohawk College, I had seen campers running around the college and one of these years; I was invited To participate with these campers. At the end of this session, I was invited to the children's talent show.

There is a private school beside Mohawk College and when I was visiting one of my friends at Mohawk College, I had decided I should visit this private school and talk with the school's headmaster about me giving a speech to this school. I had no idea what this headmaster would say to me but he loved the idea about me speaking to the high school students. He gave my email to the headmaster for the senior school and two months later, two students contacted me because they were the head girl and head boy prefects for the senior school. They wanted to meet me before I would be giving my speech to the whole senior school student body. I knew this would be breaking one of my cardinal rules to not speaking to the whole student body. However, I figured that this would be perfectly okay because these students were mature for their ages and this school had given me a great opportunity to speak to the senior class. At this meeting with the head prefects, I met other prefects and we talked about what speech I should give to the senior class. They thought I should give my life story to the Senior class. They also gave me a tour of the stage where I would be giving my speech to the senior class. This is so important to see where I would be giving my speech to the senior class because I didn't know how big the stage was and I didn't know they would have proper mic for my Pathfinder. I was a little bit nervous to speak to these students because I had no idea what they would think about my life story. However, I needed to realize that these students were just normal teenagers who were interested to hear my life story. After

giving my speech to the senior class, some prefects gave me a tour of the school. This school has plays in April and December and fair day in May and I am invited to go to these events.

In September of 2008, my local school had a new principal and I had no idea what he would say about me giving more speeches at his school. The secretary recommended that he should get to know me before making a decision. The secretary also told him that the superintendent of special education knew me. He agreed that I should speak to his school; however, I needed to write a brand-new speech for this school. This speech was about the children's extra curricular activities. Every new speech I need to write has to be interesting and fresh because I can lose the children's attention very quickly. A few times over these three years, I had to stop speaking to some classes and wait until the students were paying attention to me. This is quite normal for students to sometimes stop paying attention. Also, when the students were not paying attention to me, their teachers sometimes moved them away from other students. Once last January, I had to stop speaking to a class because one student was not paying attention to me. Then at the end of my speech, I said sorry to this student and the student said it was okay. After giving my speeches to individual grades, I let the students ask me questions and take a look at my Eco's screen. This is so important to let them to do these two things because they are very inquisitive and very interested about how I use my Eco. I would never let the adult population do these two things on the streets because they aren't children.

However, when I have chances to speak to the Personal Support Worker class at Mohawk College, I let the students take a look at my Eco's screen because they are students who are learning to be out in the community. If this could help one person with disabilities, then it is worth it. But sometimes speaking to these classes at Mohawk College is very disheartening because some students don't want to pay attention to me and their teacher doesn’t seem to care what they are doing in their class. Every October or November, two students from McMaster University's occupational therapist and physical therapist program come over to my house to shadow me. This teaches these students how to interact with people with disabilities.

Over the three years while the current principal is the head of the school, I am invited to the school's special events like school's masses at the local church, Talent Show, and graduation ceremonies. I think this principal has respect for me and can see how his students are effected positively by being around me. In the spring and summer, I like to ride my scooter around my neighborhood and the students from this school always say hello to me because they have respect for me.

In May, I had to finish up speaking to one of the schools before my speech was finished because I was running low on my Eco's battery. Oh, the joys of technology! In January, before speaking to a particular class, there was a liturgy for a higher grade at this school and I asked the vice principal if I could join this liturgy. He said yes. This school really respects me and the message in my speech. When I was leaving his school, I asked him if I write a speech about bullying, could I speak to his school next year about bullying? He said yes.

In conclusion, if you would like to speak to schools in your community, you must go to the board of education and speak with the superintendent of special needs about this. You shouldn't give up if the individual principal would say no thanks. I had a lot of rejections from the principals and I slowly realized that they haven't been educated about people with disabilities. That's very sad for them and their students. Thank you for listening to me

Work and Attendants: A Double-Edged Sword

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Managing attendant care can be challenging for the augmented communicator, &, being a part of the work force. That was certainly the case with me. I have grown immensely in, my managing of my attendant care. Admittedly, it was quite challenging, getting to this comfort level. Like anything, with time & experience, the easier it became. Today, it's my intent, to provide you with some of my experiences, in order to 1, illustrate how I manage my attendants &, 2 illustrate, that your challenges aren't unique just to you. Everyone experiences certain challenges with their attendants, once in a while.

It's important that you establish a good relationship, with your attendants, when you work because, other people can see your relationship, and it could reflect on your working reputation. In my case, my working reputation, started with establishing a good personal relationship with my attendants.

Now, they say that attendants shouldn't be friends, but, it's difficult to do. Your attendants see you, very intimately, because, they wake you up, shower you, dress you, which is done without your communication devices on. They have to understand you without your communication device. They also dress you, feed you, help you with the bathroom, & put you to bed. That's extremely intimate; however, you look at it. Then, how can you not become friends with your attendants? It's virtually impossible not to become friends with them. In fact, I'll say you should become friends, because that rapport will show at your work place. It's a matter of attitude that would make it work, just like with my attendant: Yvonne. I have an excellent working relationship with her. When I mentioned attitude, I meant on both sides: the attendants and mine. Her positive attitude &, her maturity has been a definite factor to my working success!

By the way, I have two attendants, right now. That's often the case, as you very well may know. People, in our situation, have multiple attendants. One has young

children, and also has a positive attitude: Charlene Cokely. The other has adult children. Yvonne.

For my employment, I public speak, I'm Executive Director of SHOUT, as well as, being a consultant at PaTTAN. It has been challenging negotiating attendant care, when spur of the moment, public speaking jobs & SHOUT engagements appeared. Fortunately, both of my attendants have been, extraordinary, about accommodating me, when these occurred. Of course, I prefer to have advance notice, so I could give my attendants, that, advance notice. That is only reasonable. Right? Unfortunately, we don't live in a perfect world. The fact is, there were times, when I didn't have the luxury of much advance notice. In those particular circumstances, it's important to determine which attendant, to have to accompany you. As the working augmented communicator, my challenge was to determine, which attendant to ask to accompany me, who had that flexibility. In the beginning, it was Yvonne; simply because, she didn't have young children that she had to worry about, negotiating child care. Fortunately, the people who have asked me to public speak & SHOUT; have learned to provide me with ample notice, so I wouldn't run into this dilemma, anymore. I would like to point out, that Charlene has negotiated child care, when I had advanced notice.

Since my working schedule at PaTTAN, was established to be Mondays & Wednesday at their facility, each attendant had their day to accompany me to work. On Monday, it was established to be Charlene to accompany me. Then Wednesday, was given to Yvonne to accompany me. This working schedule for my attendants was created so, I would not have attendant burnt out. It has worked well so far. Now, since Charlene has younger children, she couldn't arrive to my house, at 8 o'clock, to get me ready for work, so, Yvonne was assigned to come and shower me & get me dressed. Actually, my attendant care agency arranged this. When I have a Monday off, of course, I have gotten into the practice, of letting Yvonne & Charlene know so that, Yvonne would not come in early Monday morning, &, Charlene wouldn't wear dress clothes. That's only right, the same way, when I have taken off from PaTTAN, for vacation, or, whatever days. Yes, there were times when I have messed up, & neglected to mention that I wasn't going to work. I wasn't happy with myself, about that, but, it happens.

Up until now, I haven't shared any devastatingly negative things. I have decided to share one because, it occurred, &, I would like you to hear how I handled it.

One day when I didn't have to work at PaTTAN, I was left in bed, all day. What happened was, my attendant called off, not Yvonne or Charlene, & she did the protocol thing. She called her agency and called off, to have them call my attendant care agency to notify them, that I needed a replacement. Well, her agency didn't do the right thing. Instead, someone from that agency, called my house and left a message on my answering machine, and explained that my attendant called off, &, said if I needed a replacement, to call back. The call came at around 8 in the morning. This was a major issue! The issue was that, I was in bed without access to

my communication device, &, my parents were already at work. Therefore, I laid in bed, all day! This was NOT a good thing to have happen! Needless to say, that attendant was fired. A positive thing came out of this frightening & negative experience though. I was provided with a life line button. Now, if an attendant doesn't show, I can bump that button with my head, &, someone calls my attendant care agency, and or, back up people such as my parents. Having that life line just provided me with a piece of mind.

Before I found Charlene & Yvonne, I went through a significant number of attendants. It was quite challenging, to find attendants who were compatible with me & who would enable me, to work and to have the existence that I desired. I just had to persevere & to keep a positive attitude. I wanted to point this out so that you would understand that I went through a significant number of attendants before Charlene & Yvonne were working for me.

You have heard how I manage my attendant care, while being a part of the work force. I have illustrated some of my challenges, &, mistakes, & described how I rectified them. I did that, so you wouldn't make the mistakes that I've made. The bottom line is that I've learned that managing my attendant care and working, is a constant learning process. Yes, it may be challenging, but: it's so worth it!

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