

Upfront



You get up, get dressed, grab a bite and go to work—a familiar routine in the lives of most adults. Participation in competitive employment is, and will always be, a key component of the adult experience. Many people begin their first job as teenagers and then work consistently, or on and off, until they retire some fifty years later. As adults, people spend approximately 1/3 of each day asleep; 1/3 doing work, and the rest of each day divided between attending to basic needs and engaging in leisure activities. This is not the case for people with severe disabilities. Most never join the workforce.

Eleven years ago, I focused on the employment of people who rely on AAC in an issue of this newsletter. It was in conjunction with the first Pittsburgh Employment Conference for Augmented Communicators PEC@. As I peruse that issue and reflect, I sadly realize that not very much has changed. Back then, I wrote that there was an “employment explosion” in the AAC community.¹ Service providers were employed by governmental, rehabilitation, health care, and educational systems or were self-employed. Researchers and developers were working on projects supported by universities, companies, foundations and governments. AAC/AT manufacturers had grown to multimillion-dollar companies with sales, marketing, technical, funding and support staff. Educators were engaged in teaching students AAC-

related courses at scores of universities; and there were enough continuing education activities to keep many of us “on the road” most of the time. We had professional organizations, special interest groups, journals, newsletters, books and electronic networks with a focus on AAC. Our advocacy efforts in many countries had led to laws and public policies that mandated the right of people to gain access to the communication technologies and services they needed to communicate. Great news, right? Not quite.

There was one exception. One group in the AAC community remains unemployed—those who use AAC techniques and devices to communicate . . . the only reason the field exists.²

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For Consumers



Perspectives on employment: AAC-RERC Writers Brigade

By Sarah Blackstone with Johana Schwartz, Tracy Rackensperger, Joe Hemphill, Tom Yunkerman and Bill Geluso

I asked five adults who are participants in the AAC-RERC Writers Brigade about their employment experiences. The Brigade writes and publishes articles that describe work underway within the AAC-RERC. They range in age from 23 to 62 years, reside in the U.S. and have had a variety of employment opportunities. Their stories help personalize the vocational experiences of indi-

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viduals who rely on AAC but, as a group, they are not representative of a majority of people with complex communication needs.

All have worked as adults, mostly part time within the disability field. Their employers have included AAC manufacturers, AAC companies, universities, newspapers, disability-related organizations, the U.S. government and small businesses.

I asked questions about their current work situations, previous employment-related experiences and what their “dream job” might be. I also inquired about barriers they had faced and invited them to give advice to others who rely on AAC and may wish to work.

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Johana Schwartz is 23 years old and a recent graduate of Stanford University with a B.A. in English. While in college, she tutored freshman in writing humanities term papers. She also serves as a role model at Authentic Voices of America, a camp for people who rely on AAC. Currently, Johana is working 16 hours a week managing the AAC-RERC Writers Brigade project from her home office. She mentors the Writers Brigade partici-

pants and also writes and publishes her own articles in AAC/AT related magazines and newsletters.

Johana describes her “perfect job” as one that would employ her “skills of writing and publishing in an intellectually stimulating and socially active environment, like an office position at a publishing house or a university.” She said,

I want a position that offers exciting opportunities and exciting work within a setting that supports my use of AAC.

I want to work indoors where electrical outlets are readily available. I would

expect maximum interaction with my colleagues, but I prefer not to deal directly with the public.

Johana reported that as a child her parents made sure she met adults who relied on AAC and were employed.

My parents always envisioned that I would be employed as an adult. They ensured that I acquired skills through education to be employable.

She also said her teachers taught her the skills she uses in her work.

One teacher in high school hired me through a work experience program to act as his teaching assistant, correcting exams. In college, a professor hired me to do research for him. In each case, I initiated the position and it resulted in a favorable experience for all concerned. However, I regret that I never had a conversation with teachers about their expectations for me.

Johana says she has encountered resistance from employers outside the field of disability.

People are reluctant to hire me because they feel that colleagues or clients will be burdened by the demands of interacting with me. For example, my supervisor in the Stanford tutoring program was skeptical, despite my qualifications. She eventually acquiesced, and without regret; I earned high ratings from my students and she offered to hire me again.

Johana believes that anyone who could handle the workload of college can handle the demands of a job. She advises others to:

1. Contact your state Department of Rehabilitation (or a similar agency) to determine what support services they offer. Their mission is to insure you get training, either academic or on-the-job. They may purchase assistive technology for training or your first job.
2. Emphasize your assets and why the employer should invest in you.
3. Be self-confident and persistent. Let the employer know what accommodations you need and that you can problem solve with them to get them met. They will be more motivated to accommodate you.

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Many adults who rely on this community of AAC-related workers to make a difference in their lives, are not able to live independently, buy houses, go on vacations or support their family because they themselves are not employed. Thankfully the situation has improved. More people with severe communication impairments are working, and the capacity and aspiration of these individuals for employment is higher than at any other time in history. Comparatively, however, a still quite small percentage of these individuals are employed, even part-time.³

This issue draws attention to the employment situation in AAC, and offers an update on some of the efforts underway. In **For Consumers**, participants in the AAC-RERC Writers Brigade respond to a survey about their employment experiences.

Great Expectations reprints an article written by Michael B. Williams entitled “Think Big,” encouraging individuals who rely on AAC to think beyond working for AAC manufacturers. No issue on employment would be complete without an article on PEC@— a conference heralding the employment of

individuals who rely on AAC. **Social Networks** highlights the importance of building and maintaining social contacts to support successful job searches and ongoing employment.

International Perspective reports on the results of a small survey of colleagues from five countries; and **University/Research** shares information about studies highlighting the employment of individuals with cerebral palsy, amyotrophic lateral sclerosis and autism. The **AAC-RERC** section summarizes three research projects that focus on employment. **On the Web** gives brief descriptions of some relevant websites.

Many thanks to all who assisted me with this issue. They are listed as Resources on page 15. 

Sarah W. Blackstone, Ph.D.
Author



Tracy Rackensperger is 27 years old woman who recently received her master’s degree in Communication. She reports having worked for an assistive technology center, an AAC device manufacturer and some of the AAC-RERC partners. She currently coordinates information for distribution to the ACOLUG list serv, in addition to participating in the Writers Brigade. When asked about her idea of a “perfect” job, she said,

My ideal career would consist of implementing studies, interpreting data, coordinating and conducting presentations/trainings/seminars, composing proposals and other related activities.

Tracy is looking for full time employment in the disability field.

Most jobs I have had depend on grant funding that is project-limited and only allows for part-time work. Also, professional positions have been difficult to locate.

Tracy said her parents have always had the same expectations for her as for her sister. “They want to see me become employed full-time so I can live on my own and be able to do things as independently as possible.” She said that teachers in college and graduate school helped her acquire the experiences and skills to work. Tracy is writing more extensively about her job search in an upcoming issue of *SpeakUP* (See page 5). Her advice to others is to:

1. Develop self-confidence and determination to find jobs you enjoy.
2. Don’t lower your expectations regarding compensation, benefits or other things important to you.
3. Focus on your abilities, not your disabilities.

Tom Younkerman is in his early 50s. He never attended public school but passed the G.E.D. exam and graduated from a community college. He works as a website designer for Colorado University

twelve hours each week and describes this as the “perfect job” for him. [See www.colorado.edu/ATconference for an example.] Tom typically travels to an office on campus. However, when the weather is bad in Denver, he telecommutes. He also actively participates in the AAC-RERC Writers Brigade from his home office. In the past, he has worked writing computer programs for dentists and managing a bulletin board for Easter Seals.

Tom indicated that his parents did not expect him to be employed.

I don’t think they thought I would ever work. They would have been happy if I just stayed home, but I needed to get out and be productive.

He believes that attitudes are primary barriers to employment. “People have to give you a chance and see past the disability.” He added, “I have had to prove myself at each job that I have held.” Tom advises people to

1. Be persistent.
2. Make the most of every opportunity.
3. Do your best to communicate effectively and efficiently.
4. Prepare messages in advance.
5. Try to make the person you’re talking with feel at ease.

Bill Geluso is 54 and a computer programmer. He graduated from college in 1973 with a B.A. in geology; and his first job was as a technical writer in the environmental division of his local health department.

Unfortunately, my typing was so slow and strenuous that the Health Department did not hire me directly once the federal subsidy ended after three years.

Since then, Bill has worked to create software for organizations and individuals to their specifications. He enjoys working from home and says that computer programming is a perfect job fit.

I chose computer programming over technical/creative writing, because the amount of required physical typing in programming is very low relative to the thought process. Thus, my production rate may not differ much from a non-disabled individual.

He reports that his family and teachers always expected him to go to college.

From the sixth grade forward, all my teachers expected me to attend college and they designed a syllabus for me towards that goal. On the other hand, the principal of the special school where I went disagreed. He questioned the “need” for someone as handicapped as me to receive a higher education. He was not very enlightened. Fortunately, my teachers won this controversy.

Bill identified five barriers to employment, including his (1) slow production rate, (2) inability to physically handle reference material while writing reports, (3) inability to verbally discuss assignments with supervisors and co-workers, (4) inability to perform “secondary duties” in a job description (e.g., answering the telephone and filing) and (5) inability to communicate in a normal fashion during job interviews. However, he strongly encourages anyone with similar problems to “try!”

There’s no way of knowing if you can or can’t succeed in something if you don’t try. Of course, you must be practical, but not overly practical. Don’t be afraid of failure. If you don’t succeed, try something else. Today’s technologies—particularly e-mail, faxes and sophisticated AAC devices—provide the physically challenged with much more employment opportunities/configurations than I had after graduating college. So, try!

Joe Hemphill has had several part-time jobs during his life, including editing a newsletter on disability at Long Beach State University and writing research articles for the independent center in Anaheim, California. He graduated from high

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school and has taken university classes. He said the major employment barriers he faced were communication and transportation. Computers did not exist when he was younger, so he worked using an electric typewriter, which was “very tedious.”

Even though I worked in places for disabled individuals, it was difficult for others to take time to understand my speech because listening to me took away time that should have been spent working. Also, I had to allow two hours on each end of my workday for transportation.

Joe said he now considers a perfect job to be one in which he works at home at his own pace and doesn't have to worry about transporting his computer and setting it up somewhere else.

His parents raised him to be “as normal as possible.”

I expected to grow up and get a job. I knew it wouldn't be like other jobs that most kids got. I knew I couldn't get a job at the neighborhood grocery store.


His first job was pulling weeds for him mom. Also, his dad paid him to pull the clothes out of the dryers at the laundry he ran.

Joe attended a special school for children with handicaps and recalled that his teachers and therapists encouraged him to develop his writing skills. “They implied some day I would work on a newspaper.”

Joe's advice to others is to be competent and be flexible.

Develop your skills with your communication device or devices so you are very efficient. Be ready to adjust your abilities with communication devices to meet the needs of communicating on a job.

Summary

While the overall employment rate for people who rely on AAC is abysmal, these individuals, who are currently working for the AAC-RERC's Writers Brigade, are testimony to the potential for people to find work. With high expectations and determination and the support of parents and teachers, they are breaking through barriers. 



Great expectations

Years ago Michael B. Williams wrote about the expectations and realities of employment for people, who rely on AAC technologies. The article was entitled “Think Big.” In it, he challenged augmented communicators and the AAC community to extend their aspirations beyond the obvious.⁴

Some time ago, several of you regular ACOLUGers expressed a desire to go to work for your favorite AAC manufacturer. Now, on the face of it, there is nothing wrong with this goal. I've had similar thoughts myself. But

have you ever really considered why you want to go to work for an AAC manufacturer? Perhaps you think it will be an easy line of work. After all, you know that device of yours forwards and backwards. You probably can program it better and faster than most of the professionals. And you no doubt have a thousand ideas to improve the device. These are all good reasons to want to go to work for your favorite manufacturer.

But I want to suggest that there may be another deeper reason behind your desires. Could it be that you want to work for an AAC manufacturer because you know that you will be treated like a regular human being there? There is no need to go through any of those complicated song and dance routines about your disability. You can relax. Do your job. Blend in. Sounds wonderful, doesn't it? And it would be wonderful.

But it also would be a cop out. For the brutal truth of the matter is, there are more of us than there are of them. Even if AAC manufacturers hired all the augmented communicators they could, and, make no mistake about it, I think manufacturers should be hiring augmented communicators; there shouldn't be enough jobs for all of us. Let's face it, folks. The chances of any

one of us being hired on for a full-time job at an AAC manufacturer are about as great as the average inner-city kid getting on a team in the National Basketball Association. We augmented communicators need to set our sights beyond the disability ghetto in which we find ourselves and reach out to that wider world that's out there. That is where the money is. That is where the power is. That is where we want to be.

If we are going to dream, let's do it big. Let's not be limited by what we think we can do, let's consider possibilities that may be beyond our grasp. Let's reach for the stars. We won't touch them, but we may find something worth keeping along the way.



Michael B. Williams, author

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Pittsburgh Employment Conference



with disabilities. It's all very complicated." The PEC@ proceedings reflect the themes and describe the focus of each conference.

A decade of PECs@

Since 1993, the Pittsburgh Employment Conference for Augmented Communicators (PEC@) has focused entirely on employment issues concerning persons who rely on AAC. The idea for PEC@ was conceived by members of SHOUT, an organization consisting of interested persons from the business community, education agencies and vocational rehabilitation services in Pennsylvania, who advocate for education and opportunities for persons using AAC. PEC@ 1993, the first conference, was attended by professionals in the field and a few individuals who relied on AAC and their families. Last year over 200 participants and more than 40 adults who rely on AAC gathered in Pittsburgh for what had become an international conference.

Every year the conference has sought to highlight a different area of focus on the problems confronting adults who rely on AAC and wish to work. Early conferences were gatherings of individuals who wanted to define the problems. More recent ones have taken on themes that address the "whole" person when considering employment concerns. Recognizing that work is just one of many adult roles that are intertwined, the conference has taken many different and important directions. As Bruce Baker, chairperson of PEC@, pointed out, "Not everyone wants to, or can, work. In fact, there is always quite a bit of discussion at PEC@ about how one defines "work." Also, there are enormous costs to working for some people

- **1993.** 1st Annual PEC@, *Focus and Synergy*, Volume 1
- **1994.** 2nd Annual PEC@, *Breaking the Barriers to Employment*, Volume 2
- **1995.** 3rd Annual PEC@, *Success Stories*, Volume 3
- **1996.** 4th Annual PEC@, *Town Meeting*, Volume 4
- **1997.** 5th Annual PEC@, *Entrepreneur\$hip?*, Volume 5
- **1998.** 6th Annual PEC@, *Employment, Independence, Marriage, and Sexuality*, Volume 6
- **1999.** 7th Annual PEC@, *Can we influence the field of Augmentative Education?*, Volume 7
- **2001.** 8th Annual PEC@, *The Roles of Mentoring and Personal Care Assistants in Employment*, Volume 8
- **2003.** Biennial PEC@, *Strategies and Partners in Employment*, Volume 9


Over the years, PEC@ and its town meeting format has proliferated to other conferences where individuals who rely on AAC come together and hold "town meetings." These gatherings have occurred in the United Kingdom, Canada and on the West Coast of the USA.

Out of these gatherings, friendships are formed and a resolve is established among the attendees. Another outcome is that PEC@ raises the level of awareness of participants, particularly those who are children (and growing up)

SpeakUP! On Employment


An upcoming issue of *SpeakUP!* features *Employment and AAC*. You'll meet interesting people who are working. *SpeakUP!* highlights the accomplishments of our field and provides a forum for debate and discussion.

The cover story features India Ochs, Esq., an attorney who recently was hired by the RFK Memorial Center for Human Rights in Washington, D.C.

SpeakUP! is published by USSAAC, the United States Society for Augmentative and Alternative Communication and has a new, flashy, *People Magazine* type of "look." I highly recommend that you check it out. 

For more information, go to www.USSAAC.org.

and parents and teachers, who are setting expectations for their future.

In summary, these conferences have raised expectations and built job-related social networks, both of which are crucial to successful employment. While the future of PEC@ is not clear at this time (because of its heavy reliance on external funding), the organizers are currently actively seeking support, and planning for PEC@ 2005. 

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Social Networks



The role of social networks in employment with Diane Bryen

Dr. Diane Bryen and her colleagues at Temple University have conducted a series of studies that focus on the job-related social networks of individuals who rely on AAC. Their research explores the role of job-related networks on the employment of persons who rely on AAC devices. It also compares these networks to those of matched typical peers and investigates the role communication technologies play in developing and maintaining the social networks that enhance a person's employment experience.

Background

Most often, employment difficulties experienced by individuals with severe disabilities are explained in terms of (1) human capital deficiencies, *i.e.*, the individual's skills, abilities and/or knowledge (or lack thereof) or (2) existing social prejudice and associated societal barriers. Research has documented that poor work preparation and lack of literacy skills,^{5,6,7} financial disincentives to work,⁸ physical, environmental and attitudinal barriers,⁹ limited opportunities to hold first jobs as young adults¹⁰ and the limited capabilities of AAC devices⁵ interfere with the employment of individuals with complex communication needs.

The broader employment literature also documents that social capital and an individual's social networks can play a powerful role in obtaining and maintaining employment. Individuals without disabilities find jobs through contacts in their

social networks^{11,12,13}

Research also suggests that people who are recommended by someone in an

employer's social network

are far more likely to be interviewed and ten times more likely to be offered a job.¹⁴ This makes sense because finding a job is a process of matching a potential employee with a job opportunity. Social networks offer channels through which information can flow between potential employers and potential employees.¹⁵ Also, once employment is obtained, the development of natural supports in the workplace increases positive employment and social interaction outcomes in the workplace.¹⁶

This article summarizes research findings from Temple's Institute on Disabilities and demonstrates the importance of social networks on employment outcomes in AAC.

Description

A goal of the research team at Temple is to raise the awareness of the AAC community about the importance of building and maintaining social networks to address the employment goals of individuals with complex communication needs. Specifically, researchers interviewed 38 adults with significant communication disabilities who rely on AAC technologies. All participants were over 18 years of age, had physical and severe communication challenges and used a voice-output communication device. All were either employed or actively seeking employment.

Participants were assigned to four groups, with five or more participants in each group: college graduates employed, college graduates unemployed, not college graduates employed, not college graduates unemployed. A small comparison

sample of ten typical peers without disabilities, matched on some but not all the variables, also participated. All participants completed the Job Contact Network Survey designed by the research team for use in this study. The researchers sought to (1) compare the job-related networks of persons who rely on AAC devices to their matched peers without disabilities and (2) consider the role of communication technologies in the development and maintenance of social networks.

Comparing job-related networks.

This analysis explored the degree to which social capital is important for the employment of persons who rely on AAC technologies. Potts, Carey, Bryen and Cohen¹⁷ investigated the nature of the social networks of persons who rely on AAC with regard to the (1) size of their networks, (2) ratio of weak ties relative to strong ties in their job contact networks, (3) redundancy of the person's job contact networks and (4) social capital of their job contacts.

Preliminary findings suggest that the size of a participant's social network may affect the success of his/her search for employment. Researchers also found that the job contact networks of AAC users seem to be smaller than those of their age-matched peers. They questioned whether this might explain some of the differences between the two group's employment status. Researchers found no evidence that the prestige of one's social contacts has an impact on employment. Finally, results did not clarify whether the networks of AAC users are more redundant (*i.e.*, the extent to which social contacts in a network know one another) than those of their typical peer group.

Role of communication technologies in developing social networks. Carey, Potts, Bryen and Shankar¹⁷ investigated the extent to which generic communication technologies (e.g., telephones, email, Internet, cell phones, fax machines) have enabled participants to stay in touch with people in their network. They found that a variety of generic communication technologies are used, in addition to AAC devices. Telephones (landline), email and the Internet are most frequently used to contact the largest number of people, with email and the Internet used most often. When comparing individuals who rely on AAC with a matched group, researchers found that AAC users use telephones (landline) and cell phones less frequently than their non-disabled siblings or peers.


The data also revealed that for all groups, the most important way to meet new people is face-to-face

contact. Also, individuals who are employed make greater use of generic communication technologies than those who were not.

Both AAC technologies and generic communication technologies are perceived as helping people who rely on AAC in their job searches and job-related tasks, and in developing broader social networks. Researchers also listed ways existing technologies could be modified to better support the type of networking that can lead to employment. Examples include: (1) integrating AAC devices with generic technologies like cellular phones, computers and email, (2) having better quality speech technologies, (3) increasing communication rates and (4) improving access methods.

Summary

Researchers at Temple University have conducted studies that suggest

that access to and use of generic communication technologies, job-related social networks and employment success are interrelated. They conclude that historically poor employment prospects of persons with complex communication needs may be enhanced by focusing more directly on the development of social capital, in addition to human capital. These researchers recommend that job counselors develop a basic understanding of social network analysis so they can provide support to individuals to build their social capital. Individuals who rely on AAC are encouraged to expand their job contacts by volunteering, participating in community groups and engaging in other social activities. 

International Perspective



the sample is small and therefore not representative, but it confirms the employment situation for adults who rely on AAC is an international problem.

A preliminary survey

In an effort to investigate the employment status of people who rely on AAC from countries outside the United States, I emailed a questionnaire to a small group of colleagues from eight countries and received responses from six people (engineer, educators and speech-language pathologists). Two were from Portugal, one from Sweden, one from Canada and two from Australia. The questionnaire had statements that the respondents could agree or disagree with on a 5-point scale, with 1 = strongly agree and 5 = strongly disagree with the statement. Table I summarizes the responses. Obviously

1. *People with severe communication disabilities have good opportunities for employment.* Respondents strongly disagreed with this statement. One said, “Very few people who rely on AAC are employed, even if they are qualified. Other comments were, “It is impossible.” “It depends on the nature of the disability. Deaf have a better chance than some other groups.”

2. *We have laws in my country that are supposed to enable people with disabilities to be employed.* Respondents agreed that laws exist in their country. However, as one person said, “We have very good laws, but in practice things don’t

work because our legislation is not really backed by infrastructure.”

3. *People who rely on AAC and live in my country are finding work when they want to.* All respondents strongly disagreed that people who wanted to work were able to become employed. They said, “Individuals have trouble finding work.” “They take jobs for which they are over-qualified and miss out on promotions.” “We have a low employment rate for people with any sort of disability.”

4. *People who rely on AAC in my country are most likely to be employed full time.* Again, all respondents strongly disagreed. They said, “Often people want part-time work. Managing attendants, working, traveling, etc. is exhausting.” “I know of only three people in full time employment.”

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International Perspective, Cont. from page 7

5. *People who rely on AAC in my country are most likely to be employed part-time.* Respondents were not consistent with one another in their responses to this statement. The range was from one to five. Their responses may reflect a perceived lack of support and/or lack of advocacy, on the one hand, and references to a reality that many people who currently “work” are volunteers and/or in sheltered situations.

6. *People who rely on AAC in my country are most likely to be employed fewer than 20 hours a week.* Respondents had different responses to this statement. One comment was “It depends on the type of work. There is a range if you consider volunteer work.”

7. *Most people who rely on AAC in my country who choose to work are not employed.* All respondents strongly agreed. One also pointed out that it was “true for all people with life-long disabilities,” not just those who rely on AAC.

8. *People in my country who rely on AAC are most likely to be employed by government/public agencies.* Respondents agreed, but not strongly with this statement. One person said that individuals who rely on AAC in their country are “likely to be placed by a public agency as part of social policy or by one of the private job agencies that do government work.”

9. *People in my country who rely on AAC are most likely to be employed by non-public organizations/firms/companies in the area of disability.* The six respondents agreed, but not strongly, with this statement. Comments included: “I don’t know anymore.” “Big charities (CP) provide employment. They pay minimum wage so as not to affect allowances and pensions.”

Table 1. Data from a small sample

Question	Score	Mean	Range	Interpretation
1	28	4.5	4 - 5	Strongly disagree
2	12	2.0	1 - 3	Agree
3	30	5.0	...	Strongly disagree
4	30	5.0	...	Strongly disagree
5	19	3.2	1 - 5	Inconsistent
6	16	2.9	2 - 5	Inconsistent
7	30	5.0	...	Strongly disagree
8	13	2.1	1 - 4	Agree
9	16	2.5	2 - 4	Agree
10	21	4.2	2 - 5	Disagree
11	22	4.2	2 - 5	Disagree

10. *People in my country who rely on AAC are most likely to be employed by non-public organizations/companies outside the area of disability.* One person did not respond to this statement. The others disagreed and one person pointed out that “private sector employers are very few.”


11. *People in my country who rely on AAC are most likely to be self-employed.* Again, the respondents disagreed. Several mentioned that they knew individuals who had aspired to provide web-related services, but knew “no one who is making a living at it.” Another respondent knew two people—a mathematician (now deceased) and a solicitor who does not deal directly with clients. “The solicitor employs his wife in the business.”

The next two questions asked respondents to rank which groups they felt were most likely to be employed. They responded that the groups with developmental disabilities most likely to be employed are people with cerebral palsy, Down syndrome and severe language impairment. Individuals with severe cognitive impairment are least likely and those with Asperger syndrome,

autism and dual sensory impairments are in between. Groups with acquired conditions most likely to be employed are individuals with aphasia and multiple sclerosis, while those with ALS and Parkinson’s disease are least likely. Individuals with traumatic brain injury and other degenerative conditions affecting speech are in between.

The respondent’s advice to people seeking employment was, “Don’t count on getting a job on the common market.” “Rely on personal contacts and friends to help you.” “Don’t give up.”

All agreed that much remains to be done, including

1. Educating the general public and professions (mainly medical doctors) about the importance of AAC and how AAC can enhance quality of life and help people participate more actively in society, including having a full-time job.
2. Having an impact on the education of neurologists, who are responsible for the treatment of people with acquired disabilities and who know very little about AAC. Education in medical schools is needed.
3. Improving literacy programs and developing and implementing vocational programs.
4. Reconsidering the impact of “integrated schooling,” some parents say they are lowering employment prospects for their children because special schools were operating in closer contact with employers.
5. Providing more education to the public.
6. Addressing issues such as technology, attendant support, transportation and accessibility. Despite anti-discrimination and equal opportunity laws, community attitudes are a barrier.
7. Changing attitudes about persons with disabilities. The lack of employment among AAC users reflects our education and culture. 

University & Research



Employment of individuals with ALS, ASD and CP

with David McNaughton

Individuals who rely on AAC face issues regarding employment that can be quite diverse. The challenges they experience come not only from their physical, cognitive and/or behavioral conditions, but also from the societies within which they reside. In an effort to further define what is required for specific groups of individuals with developmental and acquired conditions to engage in successful employment, Dr. David McNaughton and his colleagues at Pennsylvania State University have focused their research on issues related to individuals with amyotrophic lateral sclerosis (ALS), autism spectrum disorders (ASD) and cerebral palsy (CP).

People with ALS

McNaughton, Light and Groszyk¹⁹ studied five people with ALS who rely on augmentative and alternative communication (AAC) and are employed. Their purpose was to (1) investigate the benefits, challenges and supports needed for sustaining

I work for a company that believes in supporting the individual who wants to remain a contributor to the company as long as possible. My company actually is quite impressed with my resolve to continue and is solidly behind me right up to the CEO. Little do they know that I simply have not learned how to quit yet while I can still do a credible job. So, with so many people supporting my efforts it's kind of tough not to try. (Frank, p.183)

employment and (2) provide recommendations to policy makers, employers and others with ALS.

Benefits and reasons for continuing employment. Individuals typically develop ALS in the midst of living productive adult lives. Thus, being told, "You have a debilitating, terminal illness," is a shock that profoundly impacts one's sense of self and all future plans. The five participants with ALS in the study reported a continued need for productive activity. Employment made them feel purposeful, sustained their income and associated benefits, and helped them maintain good mental and physical health and avoid a preoccupation with ALS. This was particularly true for those whose lifestyle was intricately connected to their employment.

I think I would tell a newly diagnosed person to be honest with his employer and with human resources. By this, I do not mean telling everyone, but people who control your employment destiny have a need to know. I think it is helpful to give these company officials something short to read on ALS so that they don't think you are going to be incapacitated and unfit to work within a very short time. (Julia, p. 191)

Supports to employment activities. All participants cited the importance of government policies and federal legislation in protecting the rights of workers with disabilities. Also, they said that the information and service delivery supports provided on the Internet and through ALS chapters and other organizations were helpful. Employer supports, such as retraining and facility accommodations, were key, as was adaptive equipment and technology with voice output. Finally, personal support networks, e.g., personal care support, moral support, financial assistance and assistance with transportation, were seen as important.

Negative aspects of continued employment. Participants also

reported that employment can have a negative impact on physical health, particularly as the ALS progresses and fatigue becomes an increasingly significant factor. In addition, participants said it was difficult to adjust to decreased job responsibilities and to deal with the negative reactions of co-workers.

Barriers to employment. The individuals participating in the study identified seven barriers that had interfered with their continued employment:

1. Technological barriers (e.g., cost of assistive technology (AT), learning demands of AT, limitations of AT and lack of appropriate fit between an AAC device and the end user.)
2. Negative attitudes toward people with ALS and terminal illness in general.
3. Policy and funding barriers, such as a lack of enforcement of government

policies, absence of employer policies to support retraining and lack of insurance funding for AT.

4. Financial barriers, such as decreased financial compensation resulting from decreased responsibilities and reduction in disability payments when salary is received.

5. Information and service barriers, including an insufficient number of organizations providing AAC services

I knew I could no longer do my job when I had to 'pick my battles' and not fight for what I knew was right... due to my inadequate speech. But I so enjoyed the stimulation that it took months for me to adjust, months when I came into work and really had no work to do. When I was eased out of my job and left with an empty title and no work to do, it was a real adjustment. (Julia, p. 186)

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to adults, lack of knowledge/expertise regarding assistive technology and inequities in services provided to people with ALS.

6. Barriers related to psychosocial adjustment of individuals, such as difficulty acknowledging ALS, difficulty asking for help and difficulty with the physical manifestations/course of ALS.

7. Lack of accommodations for wheelchairs.

Recommendations

Participants with ALS identified specific recommendations for policy makers, employers, technology developers and individuals with ALS. These are posted at http://mcn.ed.psu.edu/emp/Publications/Dont_Give_Up_v2.htm and summarized in Table II.

People with ASD

While a very small number of people with severe autism who rely on AAC are employed, expectations are increasing and people on the moderate-severe end of the autism spectrum are beginning to work in their communities with appropriate supports. Individuals with autism who use AAC and who maintain employment are described as productive (strong work ethic), capable of communicating basic needs and wants and able to understand simple instructions. In addition, they show a low rate or absence of antisocial behaviors and some positive pro-social behaviors

Table II. Recommendations: Enabling Individuals with ALS to Work (McNaughton et al., 2001)	
TARGET GROUP	RECOMMENDATIONS
POLICY MAKERS	<ol style="list-style-type: none"> 1. Enforce laws that support the rights of people with disabilities. 2. Increase prevalence of long-term care insurance. 3. Increase funding of assistive technology. 4. Provide options for leasing of equipment. 5. Support equipment exchange programs. 6. Guarantee access to medical insurance for all. 7. Ensure availability of personal care service. 8. Ensure availability of transportation services.
EMPLOYERS	<ol style="list-style-type: none"> 1. Learn about ALS. 2. Facilitate changes in job responsibilities. 3. Provide training for new jobs that are more appropriate. 4. Provide computer training for Internet access and for communication. 5. Increase the training of service providers in ALS and AAC.
TECHNOLOGY DEVELOPERS	<ol style="list-style-type: none"> 1. Decrease learning demands. 2. Provide instruction/documentation on the Internet. 3. Develop lighter, smaller, more portable systems. 4. Design more attractive systems. 5. Increase diversity of functions in systems (e.g., cellular phones). 6. Increase battery life.
INDIVIDUALS WITH ALS	<ol style="list-style-type: none"> 1. Seek out and share information about ALS; educate employers and co-workers regarding ALS. 2. Be knowledgeable; know and understand applicable legislation. 3. Recognize that ALS will require changes in job and lifestyle. 4. Propose accommodations to facilitate continued employment. 5. Advocate for yourself and others with ALS. 6. Acknowledge ALS, learn AAC technologies early. 7. Make decisions based on personal preferences and needs.

(e.g., smiling, making appropriate greetings).

McNaughton, Light and Gulla²⁰ conducted a study of individuals with ASD who use AAC to ascertain what factors influenced successful employment. They used single case descriptions to gather information from the employers, family members and communication specialists of three employed individuals with autism and identified five important factors: (1) a good job match, (2) willing employer and co-workers, (3) intensive

support early in the training process, (4) ongoing support (at reduced levels on a long-term basis) and (5) an advocate in the workplace. All three employed individuals with autism who use AAC were valued not only for the work they performed, but also for the positive social atmosphere they brought to the workplace.

As a result of the study, the researchers have provided several examples of individuals engaged in successful employment. Peter, who is 31 years old and lives at home with his father, provides one illustration of how careful attention to an individual's skills and strengths can result in positive employment outcomes. [See Peter's job search.]

McNaughton et al. found that most positive job searches involved networking with family members and other concerned individuals. The researchers report that working

Table III. Job match for Peter (McNaughton, 2004)			
	Clearing Tables	Stocking shelves	Bagging Groceries
Job Match	Good	Fair	Very Good
Strengths	Familiar	Close to home	Year Round Friendly people
Weaknesses	Not learning new skills 1 to 2 hours per day	Seasonal	Long taxi ride Employer?

Peter's job search

Peter can follow two and three step commands, uses some speech that is understood by familiar partners and has a “Hip Talk” device programmed with 6-8 phrases (e.g., “How are you?”). Paying close attention to details and completing functional routines (e.g., cleaning tables) are considered strengths. Safety issues (he cannot ride public transportation independently) and a lack of assertiveness are challenges for Peter. From his family’s perspective, the major goals for employment were to find a way he could be out of house for four hours per day and could earn some money for social activities.

Peter’s team identified several ways he might accomplish these goals. These included cleaning tables at school, stocking shelves at a dollar store and bagging groceries at the local supermarket. They then considered what would be a “good job match” for Peter. All agreed it would be important for him to be around other people so he could use his good receptive vocabulary. However, there could not be extensive expressive communication demands. It was also decided that his employer should value carefully completed work, while allowing Peter to work at a slow steady pace.

As a result of an analysis by the team (see Table III), a decision was

made to support him in learning to bag groceries at the local supermarket. Some staff at the store initially had questions about Peter’s ability to do the job. The employment team collected data on other “baggers” at the store with regard to attendance and efficiency and demonstrated that Peter was one of the few employees who regularly showed up for his shift and who followed all of the required bagging steps (e.g., thanking each shopper, in his case by using his HipTalker). While Peter still experiences difficulty with novel situations (e.g., if a customer forgets a bag of groceries), he has become a valued employee at the supermarket.

with the Office of Vocational Rehabilitation and taking advantage of seasonal work can provide good job opportunities.

Recommendations

A primary consideration for individuals with autism is to select a job that is a good match for the individual. This requires an understanding and acceptance that some events, such as a change in routine, can trigger challenging behaviors. Careful thought needs to be given to expectations of the job site. For family members, knowing that the individual was in a safe place with supportive co-workers was as important, if not more important, than any wages received. In this study, a good job match and the provision of appropriate support led to positive outcomes for the individuals with autism, their family members and their employers. Additional details are available at <http://mcn.ed.psu.edu/emp/Presentations/Autism.htm>.

People with cerebral palsy

McNaughton, Light and Arnold²¹ conducted an Internet-based focus group of eight individuals with cerebral palsy who use AAC and are employed full-time. The goals were to (1) investigate the successful employment experiences of these individuals and (2) make recommendations to improve employment outcomes. A focus group discussed several themes, including the benefits of employment and supports underlying employment success, the negative impacts of employment on individuals and barriers to employment activities.

I think there are several reasons why I want to be full-time and I would bet they're the same reasons as the rest of the working population. I have dreams of doing different things with my life, like owning my own home, getting married and having kids, going to different places, all of which take money! (Gary, p.65)

Benefits of employment. Participants identified several benefits to being employed full-time, including the experience of success, increasing self-esteem, using one’s mind and education, meeting financial needs, becoming independent and having an impact on the lives of others with disabilities.

Employment supports. The focus group identified several important supports that had enabled them to maintain full-time employment. These included (1) personal characteristics, such as a commitment to employment, strong work ethic, determination, and time management skills, (2) good educational background, volunteer experience and previous work experience, (3) technology supports (including using specific device features that support participation, e.g., voice output), posting a resume on the Internet, (4) legislation (e.g., ADA), government programs (e.g., vocational rehabilitation),

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government funding for personal care attendants, (5) family supports (specifically transportation to work and personal care) and (6) mentoring and networking with coworkers and supervisors in the workplace.

Negative impacts of employment. Participants also identified aspects of employment that have a negative impact on their lives. These included fatigue and decreased time available for activities of daily living, for social activities/personal time and for advocacy. In addition, they noted that the attitudes of some co-workers were difficult to deal with.

But the REAL barriers, in my opinion, are people's stagnant and outdated attitudes toward persons with disabilities, especially people with speech disabilities. (Joe, p. 66)

When people see me, they do not see me. They just see a person in the wheelchair. During the job interviews, they asked me how I would teach students. At that time, I had a teaching credential and advanced degrees. (Michael, p. 66)

Barriers to employment.

Participants cited 12 barriers to full-time employment. These included (1) attitudinal barriers (negative attitudes of society and employers toward individuals with disabilities, (2) educational barriers (inappropriate educational preparation), (3) technological barriers (limitations of AAC technology, breakdowns, limited technology support services, (4) lack of funding for assistive technology, (5) problems with vocational rehabilitation services (inefficiency, under-representation of individuals with disabilities in the vocational rehabilitation system), (6) a lack of reliable personal care

Table IV. Recommendations: Enabling Individuals with Cerebral Palsy to Work (McNaughton et al., 2002)

TARGET GROUP	RECOMMENDATIONS
POLICY MAKERS	<ol style="list-style-type: none"> 1. Provide public education to dispel myths about people with disabilities. 2. Enforce disability civil rights legislation (e.g., ADA) more rigorously. 3. Make income spent on attendant care and assistive technologies nontaxable. 4. Institute a systematic change of the vocational rehabilitation system (i.e., more personalized services, greater consumer control). 5. Mandate the establishment of Speech-to-Speech outreach services and teach
EMPLOYERS	<ol style="list-style-type: none"> 1. Allow individuals with disabilities the opportunity to prove their abilities.
TECHNOLOGY DEVELOPERS <small>with speech impairments.</small>	<ol style="list-style-type: none"> 1. Develop a real-time translation program that understands the speech of 2. Develop hands-free access to the on/off option of AAC devices. 3. Develop a wider range of easily portable AAC systems. 4. Develop a way for users to have private telephone calls. 5. Develop an AAC system that can vocalize thoughts. 6. Improve the integration of AAC systems and computer technologies through better collaboration between AAC and computer manufacturers. 7. Include AAC users on the device development team and pay them well.
OTHERS WITH CEREBRAL PALSY	<ol style="list-style-type: none"> 1. Study areas in which you do well. 2. Be persistent. 3. Make use of all available resources for attaining and maintaining a job (e.g., the Internet, vocational rehabilitation services, legal action, and coworkers' expertise).
EDUCATORS	<ol style="list-style-type: none"> 1. Know the abilities of students with disabilities. 2. Provide appropriate and challenging instructional activities. 3. Prepare students with the necessary skills to be productive adults. 4. Inform students about job options. 5. Provide opportunities to practice interviewing skills.


attendant services and (7) difficulty scheduling transportation and long travel times to work.

Recommendations

The participants made recommendations on ways to improve employment outcomes for individuals with cerebral palsy who use AAC devices for other AAC users, educators, technology developers, employers and policy makers. These are listed in Table IV and further discussed on http://mcn.ed.psu.edu/emp/Publications/getting_your_wheel_v2.htm.

Summary

The hope is that, by building upon our knowledge of important supports and barriers for specific groups of individuals who rely on AAC, the situation will improve. As a result, the researchers hope that

the employment success, which is true for only a handful of individuals today, will become accessible to many more individuals in the future. 

AAC-RERC

SPREAD THE WORD

Telework, adult vocabulary and ACETS online

Since 1998, the AAC-RERC has conducted a number of projects that focus on employment. Drs. David McNaughton and Janice Light and their colleagues at Pennsylvania State University and Dr. Diane Bryen and her colleagues at the Institute on Disabilities at Temple University have reported that while access to appropriate technology is pivotal to successful employment outcomes, even those with sophisticated technology skills often face significant attitudinal, architectural, transportation and communication challenges in traditional office work environments.³

In an effort to improve the employment situation for individuals who rely on AAC, current AAC-RERC projects are focusing on (1) telework as an employment option, (2) developing adult vocabulary and symbols that specifically address adult communication needs and (3) providing an online ACETS training program.

Telework project

Pennsylvania State University researchers have embarked on a project that explores the potential of telework, meaning the use of work-related activities that take place primarily outside the normal work setting and are made possible by information and telecommunication technologies. The benefits of telework that are cited include transportation concerns being minimized, access to technology being customized in one place, not moved around, and attendant care

services being more easily accessed. A disadvantage is the potential for employees to feel isolated or to be excluded from advancement opportunities. A hybrid situation would be a combination of traditional office work and telework.²²

The Penn State project, *Developing employment supports and strategies to allow integration into the workplace*, recognizes the need for Internet-based employment support and training for people who rely on AAC. David McNaughton (PI) and Tracy Rackensperger (co-investigator) will initially identify key barriers and required supports for successful employment. Then they will design a telework model to support employment and encourage employers to hire individuals who rely on AAC. Finally, they will conduct an Internet focus group of eight individuals who currently are using telework.

In 2005, the second phase of the project will begin. Participants will include six individuals who use AAC and are seeking work, employers, co-workers and employment support personnel. The goal is to develop information for individuals who rely on AAC, employers and employment support personnel. Strategies will include an accessible website that is meant to both support the employment process, as well as interest potential employers in hiring individuals who rely on AAC technologies.

Adult vocabulary

Diane Bryen and her staff at the Institute on Disabilities at Temple University are working to identify socially-valued vocabulary and symbols that promote effective and efficient communication in specific contexts and thus can enable adults who rely on AAC to more easily

fulfill adult roles they value. The research plan is to identify vocabulary sets and make them available to commercial manufacturers for broad distribution. In an effort to identify socially-valued adult vocabulary supports, the researchers are conducting online focus groups in six relevant areas: 1) the college experience, 2) social networks across the age span, 3) managing personal care assistants, 4) being a parent or intimate partner, 5) sexuality and 6) reporting crime or abuse to police or in court.

A vocabulary set on employment is already available. Researchers said, "We were alarmed at the lack of employment vocabulary available. Each system we reviewed lacked such basic employment-related terms as employment, boss, salary etc..." Go to <http://www.aacvocabulary.com>.

As more vocabulary sets become available, they will be posted on the website.

ACETS Online,

ACETS Online is another project underway at Temple's Institute on Disabilities. Augmentative Communication Employment Training and Supports (ACETS) is a program that was designed to increase the employment outcomes for people with significant communication difficulties who rely on AAC. It was field tested in 1999 and 2000 as an intensive, week-long program with one-year of follow-up support. In 2001 ACETS was also implemented in a public high school for students with severe disabilities.

ACETS Online seeks to apply lessons learned since 1999 in an electronic format program that will extend beyond the geographical boundaries of a university setting and offer help to individuals who seek

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employment via the Internet. The ACETS training program will address the development of employment-related goals, increasing job skills, social networking online, an ongoing participation through the use of a listserv, email, online “chatting” and teleconferencing programs. ACETS strives to support participants in developing and realizing their individual employment goals using a “person-centered” model. Participants will engage in a number of activities that help them define a career goal and identify additional training needs. Every participant leaves the program with an action plan for continued career growth. In ACETS Online, participants will get feedback regarding completion of their goals, problem solving to eliminate barriers, locating resources, facilitating team building.

For additional information about these and other AAC-RERC projects go to www.aac-rerc.com where you can sign up for the new, quarterly AAC-RERC e-newsletter. AAC-RERC



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On the Web



Employment info on the WWW

Unlike a decade ago, there is now some information on the Web that addresses the employment of persons with severe disabilities. Some examples follow:

<http://www.diversityworld.com/Disability/index.htm>. Lists resources, including a free monthly e-newsletter and online groups on self-employment.

http://www.opm.gov/disability/hrpro_8-04.asp. Information about federal mandates for hiring people with disabilities at all levels of government in the U.S. [Office of Personnel Management]

<http://www.cds.hawaii.edu/pdf/new/final.pdf>. A manual that covers both employment and instructional issues. A *Model for Accessibility* includes an “Accessibility Checklist” and “Requirements for Meeting Setup”. [University of Hawaii]

<http://www.ncset.org/publications/viewdesc.asp?id=1222>. A guide for parents on work-based learning and future employment. *Preparing Youth for Employment* includes references and suggested readings. [National Center on Secondary Education and Transition—NCSET]

<http://www.accessibilitydirectory.ca/index.cfm>. Helps employers find the right products and services to make their workplaces accessible. [Ontario March of Dimes in Canada.]

<http://www.shrm.org/diversity/hottopics/talent.asp>. Makes the case for more focus on employing people with disabilities. *Where Will Employers Find Talent in the 21st Century?* Includes “best practice” profiles of proactive companies. [Katherine McCary, VP of Human Resources at Sun Trust Bank and Chairperson, Virginia Business Leadership Network]

http://www.dinf.ne.jp/doc/english/other/wz_employmentpro_e.htm

Better employment prospects for disabled Japanese? (June.2001). The author of the article

discusses recent law in Japan and compares it to laws in the USA. He suggests that “working is one of the fundamental rights of human beings.” The site is a good jumping off place to learn more about the disability rights movement in Japan.

<http://www.worksupport.com/Topics/employment.asp>. A primer for recruiters and others who may be unfamiliar with interviewing people with disabilities. *When the Job Candidate has a Disability* is part of the FastFacts series. [WorkSupport program of Virginia Commonwealth University]

<http://www.entrypoint.org>. ENTRY POINT helps place undergraduate and graduate students with disabilities into paid summer internships and co-op programs throughout the U.S.. Employer partners include IBM, Texas Instruments, NASA, the National Institutes of Health, the National Science Foundation, and J.P. Morgan Chase. Employers provide competitive pay, on-site mentors, workplace accommodations and assistive technology as required. Among ENTRY POINT alumni, 92% are either employed in permanent jobs in their fields, or are in graduate programs of their choice. Applications accepted in spring of each year. [American Association for the Advancement of Science]



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Resources

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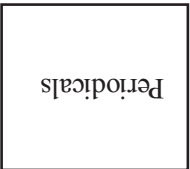
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