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“My Dream Was to Pay Taxes”: The Self-Employment Experiences of Individuals who use Augmentative and Alternative Communication

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Abstract

Seven self-employed individuals with cerebral palsy who used augmentative and alternative communication (AAC) participated in a focus group discussion conducted on the Internet. Six themes emerged from the discussion: (a) description of employment activities, (b) benefits of self-employment, (c) negative impacts of self-employment, (d) barriers to employment, (e) supports to self-employment, and (f) recommendations for improving self-employment outcomes for individuals with cerebral palsy who use AAC. For the individuals in this study, self-employment provided financial benefits, meaningful work activities, and an opportunity to realize personal expectations for participation in society. Negative societal attitudes and limited educational experiences were identified as major barriers to employment, while personal characteristics such as a willingness to take on challenges and an interest in demonstrating personal competence were seen as important supports.

Keywords: severe disability, augmentative and alternative communication, employment, self-employment, assistive technology, cerebral palsy

1. Introduction

There are approximately 2 million individuals in the United States for whom speech does not meet all of their communication needs [11]. Individuals may experience difficulty in using

speech for a variety of reasons, including both congenital disabilities such as cerebral palsy, as well as acquired conditions such as head injuries or amyotrophic lateral sclerosis [2]. In recent years, the development of innovative augmentative and alternative communication (AAC) technologies, including electronic speech-generating devices, has helped many individuals with severe communication disorders to become active participants in society [6,12]. AAC technologies have enabled individuals with severe physical and communication disabilities to successfully participate in the community, as well as in academic and vocational settings [1, 13, 20].

There are a wide variety of AAC technologies available for use. Electronic systems can range from simple units with a small number of pre-recorded messages to sophisticated computer-based devices with text-to-speech, word prediction, and environmental control capabilities. Non-electronic systems (e.g., alphabet and word boards) or unaided systems (e.g., sign language, gestures) are often an efficient means for communicating short messages to familiar partners, and are an essential back-up when high tech systems break down [2].

The use of these assistive technologies has provided new opportunities for individuals who, in the past, were rarely involved in educational or vocational activities [9]. Recent research provides evidence that, with appropriate instruction and

ongoing support, individuals who use AAC can successfully secure and maintain employment. McNaughton et al. [13] described the workplace experiences of eight individuals who used AAC and were employed full-time in community-based competitive employment situations. Educational and vocational training, community networks, and government policies were identified as important supports for obtaining employment. Assistive technology, supportive coworkers, and personal care assistance were described as important supports for maintaining employment.

Both employees and employers benefited from these work activities. McNaughton et al. [15] described the experiences of 14 employers and co-workers who worked with individuals who use AAC. Employers and co-workers reported positive attitudes concerning the employment of individuals who use AAC. A variety of supports, including the identification and development of good job matches, educational and vocational preparation, AAC technology, and the availability of transportation and personal care services, played important roles in successful employment outcomes.

While there is evidence that at least some individuals who use AAC are finding employment, many individuals with severe physical and communication disabilities still face significant barriers in entering the workforce. The most recent data indicate that less than 10% of individuals with severe physical disabilities are employed [22] and that the employment rate for individuals who have both severe physical and communication disabilities is even lower [9].

Individuals with severe disabilities face many challenges in entering the workforce. Barriers include transportation issues, negative societal attitudes about individuals with severe disabilities, and problems finding qualified personal care attendants [12]. Perhaps most challenging is the issue of communication in the workplace - individuals who use AAC identified that, despite advances in AAC technology, difficulty with communication was the largest barrier to success [9].

Between 35% and 90% of time in the workplace is spent in conversation [16]. Employers place a priority on strong communication skills, and Greenwood et al. [4] reported that over 50% of the employers are hesitant to place individuals with communication challenges in anything other than lower-level production jobs. While recent innovations in AAC technology have provided access to new methods of communication for individuals with severe disabilities, serious challenges to work force participation remain.

Faced with barriers in the traditional workplace, some individuals who use AAC have investigated self-employment. Recent studies provide evidence that self-employment can be a viable option for people with disabilities. Seekins [19] reported that people with a disability were nearly twice as likely to be self-employed (14.7% vs. 8%) as people without a disability. Hagner and Davies [5] described eight individuals with cognitive disabilities who operated their own businesses. From a strictly financial perspective, most of the businesses either “broke even” or required subsidies. At the same time, all of the participants enjoyed their work, and self-employment provided a good match with their lifestyle preferences and values.

1.1 Research Objectives

At present, little is known about self-employment as an option for individuals who use AAC. In order to implement changes that will result in positive employment experiences for individuals with cerebral palsy who use AAC, it is important to fully understand the barriers and supports to successful employment for this population. The purpose of this study was to investigate the use of self-employment by individuals who use AAC and to answer the following questions with respect to self-employment for individuals who use AAC. The specific objectives of this study included gathering demographic information regarding individuals who had cerebral palsy, used AAC, and were successfully self-employed; identifying the types of employment activities in which these individuals participated; identifying the positive and negative impacts of self-employment; determining barriers to employment,

and supports required for successful self-employment; and finally, identifying recommendations for improving self-employment outcomes for other individuals with cerebral palsy who use AAC.

2. Method

2.1 Design

A focus group methodology was employed to gain a better understanding of the self-employment experiences of individuals with cerebral palsy who used AAC. Traditionally, focus group participants are required to gather for a discussion in one location for a period of one to three hours [24]. However, there are only a small number of individuals who use AAC and who are successfully self-employed. Therefore, the focus group used in this study was conducted on an Internet bulletin board system. This forum allowed the seven participants to join the discussion from their homes without having to travel. It also allowed the participants to contribute to the discussion at a rate and time that was convenient for them.

2.2 Participants

Participants were selected based on the following criteria: (a) primary diagnosis of cerebral palsy, (b) currently self-employed for a minimum of 10 hours per week, (c) speech was inadequate to meet their daily communication needs, and (d) used AAC systems to communicate.

Participants were recruited using four techniques: (a) announcements posted in consumer newsletters; (b) direct mailings to individuals who met selection criteria and were known by the researchers; (c) contact via e-mail with rehabilitation professionals who provided services to individuals with CP who required AAC; and (d) notices on disability-related listservs.

Seven males participated in this study. Participant ages ranged from 22 to 49 years. All participants had a primary diagnosis of cerebral palsy and used either a power or manual wheelchair for mobility. Individuals' educational background ranged from completion of a high school diploma to completion of bachelor's degree and some graduate

coursework. The participants used a variety of AAC systems: three used Liberators¹, two used Dynavox 3100² systems, one used a Vanguard³, and one used an E-tran board with letters⁴. Length of use for current AAC systems by study participants averaged 8.5 years with a range of 2 months to 25 years.

Three participants used a finger or fingers to directly access their AAC device, two used head-sticks, one used his left big toe and a trackball, and one used eye-gaze pointing. For written communication three participants wrote with a desktop computer using a standard keyboard. Some individuals used an adapted interface to operate their computers, including their AAC devices, an Intellikeys adapted keyboard⁵, and an on-screen keyboard controlled with a HeadMouse⁶. Information on the specific demographic characteristics of the participants is available in *Table 1*.

¹ The Liberator is a dedicated, voice output communication device. Additional information is available from the Prentke Romich Company, 1022 Heyl Road Wooster, Ohio, USA 44691 and at www.prentrom.com.

² The Dynavox 3100 is a portable voice output communication device that uses a dynamic display and synthesized speech. More information is available from Sentient Systems, 2100 Wharton Street, Pittsburgh, PA, 15203, and at www.dynvoxsys.com

³ The Vanguard is a dedicated, voice output communication device. Additional information is available from the Prentke Romich Company, 1022 Heyl Road Wooster, Ohio, USA 44691 and at www.prentrom.com.

⁴ An E-Tran board is a large, square, plexiglass AAC system that allows an individual to indicate selection of letters via eyegaze.

⁵ IntelliKeys is a programmable alternative keyboard that plugs into any Macintosh or Windows computer. More information is available from Intellitools, 1720 Corporate Circle, Petaluma, CA 94954

⁶ The HeadMouse acts a standard computer mouse for people with severe disabilities. The wireless sensing technology employs infrared light to track a small disposable target that is placed on the user's forehead or glasses. More information is available from Origin Instruments Corporation, 854 Greenview Drive, Grand Prairie, Texas 75050-2438, USA and at <http://www.orin.com/access/headmouse/> The HeadMouse can be used with an on-screen keyboard, a virtual keyboard on the computer screen that allows people with mobility impairments to type data.

2.3 Materials

ConferWeb 2.1⁷, a password-protected Internet bulletin board system, was used for the focus group discussion on the Internet. ConferWeb allows text-based discussions of multiple topics among several individuals using the Internet. A main index page organizes the topics and provides links to the topic sites. Participants can read the postings by the other participants, and post messages to the conversation by entering their names and response into a designated “comment” area.

2.4 Procedures

Once participants had provided their consent to participate, they were sent a brief questionnaire through electronic mail to gather background information regarding their current self-employment activities, previous employment, and their use of AAC. Participants received information on joining the focus group discussion after all of the participants completed and returned their questionnaires.

The procedures for the focus group discussion were based on the best practices recommended by Vaughn et al. [24], and were adapted to meet the needs of an Internet-based focus group as recommended by McNaughton et al. [14]. Prior to beginning the focus group discussion, participants were provided with directions for the use of the site. All participants demonstrated basic competence in accessing and posting messages to the discussion site on ConferWeb. A “Welcome” page was established at the site to give participants an opportunity to practice posting messages and to introduce the members of the focus group to one another.

The first author served as the moderator for the focus group and was responsible for presenting the discussion topics, recognizing contributions and encouraging dialogue, and regulating the discussion as needed (e.g., redirecting the discussion, requesting participation). Following the introductory

messages, the moderator began to introduce topics for discussion, with a new topic introduced on the home page approximately every 5 days. The participants were asked to visit the site at least three times per week, and to respond to the questions posted by the moderator as well as the contributions of the other members of the focus group. The following topics for the questions were identified before the focus groups began: benefits of self-employment, supports to self-employment, barriers to employment, recommendations to government, recommendations to AAC manufacturers and technology developers, and recommendations to teachers, (see Appendix A for a complete list of the questions posed by the Moderator throughout the discussions).

The focus group continued for an eight-week period. During this time, the participants posted 108 comments, a total of 18,184 words, to 9 discussion questions.

2.5 Data Analysis

The text from the web-based discussion was saved to a word processing document. Participants’ postings were then unitized according to Lincoln and Guba’s [10] definition of a unit as “the smallest piece of information about something that can stand by itself...interpretable in the absence of any additional information other than a broad understanding of the context of the inquiry in which it is carried out” (p.345). The unitized data were then placed into a table containing four columns: (a) each participant’s identification code; (b) the title of the discussion strand in which the posting was entered; (c) a numeric code for the coding theme; and (d) the unitized datum (i.e., participants’ comments). The units were reviewed and organized into themes on the basis of topic and content. During this process, operational definitions for the sorting of information were developed. These operational definitions were used to code samples of text, and the operational definitions were reviewed and modified, as necessary. Six major themes were identified through this coding process: description of employment activities, benefits of self-employment, negative impact of self-employment activities, barriers to

⁷ Additional information on ConferWeb is available at <http://www.caup.Washington.edu/software/conferweb/>

employment, supports to self-employment, and recommendations to others. Appendix B contains the operational definitions of the coding themes.

The researcher assigned a numeric code to the unitized data based on the content of the statements and the operational definitions of the themes. After all of the data had been coded, a reliability check was conducted. Twenty percent of the data were selected at random to be coded by both the researcher and a graduate student who had received training in the operational definitions of the coding themes and coding procedures. An agreement score of .94 was calculated using Cohen's Kappa, a procedure that corrects for chance agreement among observers in situations in which a response can be categorized into one of a number of categories [21]. Kappa values above .81 are considered to be highly reliable [8]. Disagreements were resolved through discussion.

3. Results

The results for this study are discussed in this section, including the response data for the six major coding themes: (1) description of employment activities; (2) benefits of self-employment, (3) negative impact of self-employment, (4) barriers to employment, (5) supports to self-employment, and (6) recommendations for improved employment outcomes for individuals who use AAC. (See Table 2 for *Coding Themes, Subthemes, and Examples of Issues Raised by Participants*).

3.1 Description of Employment Activities

The self-employment activities of group members were highly varied and included: artist, software consultant, freelance journalist, freelance speaker, and web-site developer. Five of the participants engaged in additional part-time income generating activities in addition to the major self-employment activity listed above, while two focused their efforts solely on their self-employment activity. Of the seven participants, five described their employment income as supplementary to benefits received from the government, one as a supplement to their main source of income, and one declined to answer the questions. Information on the

employment characteristics of the participants is available in *Table 3*.

3.2 Benefits of Self-Employment

Examination of the benefits of self-employment resulted in the identification of four subcategories: financial benefits, enjoyment of work activities, fulfillment of personal expectations, and promotion of societal change. Some of the benefits were related to employment generally, while some were specifically associated with self-employment.

3.2.1 Financial benefits

Participants placed a priority on the financial benefits of self-employment, both with respect to being able to provide for themselves and their dependents, and also for the dignity and decision-making associated with some degree of financial independence.

Some individuals had dependents for whom they felt responsible; Phil wrote: "I also want some dignity to be able to take care of my wife like a good husband". Many participants spoke of their reluctance to accept government support, and their interest in becoming self-supporting: Sam expressed his discomfort at his reliance upon government programs (prior to self-employment) to support himself, saying "Everything I had came out of the public's tax money." The first time Sam paid for items with his own money, he described it as a very moving experience: "I cried at the check-out counter because this is the freedom that a pay check will give me...Picking out my own stuff will add value because nothing will feel like a hand-out, I won't have to wonder what medical assistance will and won't get for me." Ron also commented on the importance of employment in his life, noting that "making money isn't why I work, but it gives me dignity."

While income from self-employment activities may not have been sufficient to cover all expenses, for many the income was used to supplement government benefits. Government payments typically covered basics, although not all respondents felt it did even that well. When asked his reason for self-employment, Bob replied "My

answer has to be that I have grown accustomed to eating!”.

Income to supplement government programs was especially important when participants wanted to change their life situation by moving or getting married. Phil wrote “[Being self-employed] is good because I need money to plan my wedding on June 16th and the state doesn’t allow enough money for anything extra.” He went on to say: “I barely live off that [\$500] on my own!”.

3.2.2 *Enjoyment of work activities*

While the goals of dignity and financial independence were important, enjoyment of work activities was also a frequently identified benefit of self-employment. Carl, a free-lance speaker and assistant youth pastor, wrote the following: “The best part of my job now is I am making a huge impact on the lives of teenagers. I am impacting their lives in a positive way.” Bob, a free-lance journalist who also did presentations to college classes, made a similar comment: “I suppose on my altruistic side I get a high, knowing that I’m contributing something to society and to the betterment of person-kind.”

Being in control of their workload was important to many of the participants. Paul liked the fact that being self-employed “gives me time to do my hobbies”. On the other hand, some liked the fact that self-employment left them free to work as much as they wanted. Ron, a motivational speaker, author, artist, and assistive technology consultant reported that he liked to work, especially at a variety of activities: “The real reason I work then is that I am a person that has to be doing something constantly or I wither up.”

Participants also liked the control and independence that came from being self-employed. As Phil wrote, “That is why I love selling my pottery because I put the work in at my own pace and set my own price. No one can tell me what price to set.”

3.2.3 *Personal expectations*

Employment played a key role in helping participants meet their personal expectations for their life. Participants clearly wanted to be

contributing members of society, an expectation that typically was not held for them by others. Sam described how the assumption that he did not pay taxes made him feel excluded: “It was generally assumed that I didn’t pay taxes, so it just felt degrading.” When Sam first started to receive a small income from his business, he was instructed to discard his W2 forms by the staff of the nursing home he lived in: “That was very hurtful [instruction to throw out W2] for me because my dream was to become a tax payer.” Sam went on to describe his desire to contribute financially to society, stating “I didn’t feel a part of anything because my income never went back to help pay for the city that I live in....Now that I am employed I feel human, I feel alive.”

Finally, the participants reported that they preferred self-employment as an alternative to the unsatisfactory job opportunities that they had been offered previously. Carl refused to settle for employment that did not challenge his skills: “I have been offered several jobs in the last year, but all these jobs I am over-qualified for.” Bob, expressed his dissatisfaction with the job market, and matter-of-factly decided he was better off being his own boss: “While I’m waiting for the business world to become enlightened (about people with disabilities), I’m doing the self-employment scene.”

Some participants enjoyed the fact that in meeting their own expectations, they had exceeded the expectations of others. John wrote: “After I turned 18, all they thought I would do was sit home or go into a workshop. Well, I guess I proved them wrong.”

3.2.4 *Societal change*

The participants frequently discussed the impact of their work activities on societal attitudes. While participants recognized that many individuals in society have very low expectations for individuals who use AAC, at least some of the participants believed that continued interaction between individuals who use AAC and the general public would help to reduce these misconceptions. Carl described his efforts to rid himself of this constraint:

As I continue to travel around the area and speak, I amaze people because I shatter the

“box” they had put me in. Now over time that opinion starts to change, and pretty soon the ‘box’ they had put me in is no longer in use. I see people in society changing their attitude towards us. I am committed to opening people’s eyes and hearts to this reality.

Sam also stated his belief that “the box” will disappear with time: “The people that really get to know you won’t see you in a box.” Some of the most rewarding moments for the participants in this study came from witnessing firsthand the change in people’s opinion about individuals who use AAC. Sam, a musician, experienced this change while performing in public: “...in my show, they see me making the very best out of what I have, and I give them strength.”

3.5 Negative Impact of Self-Employment Activities

Despite the benefits of self-employment, the participants also identified two negative impacts of self-employment: the reduction of government benefits because of self-employment income, and dealing with the societal prejudice that sometimes accompanied work activities.

3.3.1 Financial restrictions

The negative impact of earned income on government benefits was a major source of frustration for participants. Ron described his view of the government’s policy of reducing benefits when earned income increases: “I often consider myself a fool for working when the government slaps me in the face for doing so.”

3.3.2 Workplace prejudice

Participants reported that prejudice in the workplace affected them in a variety of ways. On some occasions, the quality of their work was “under-valued”. Paul, who at one time had helped to produce a newsletter for children, wrote “I only got \$40 a month and this (making the newsletter) was a lot of hard work for me...it seems like I was doing all this work with 100% effort and being taken advantage of because I was disabled.”

Participants also discussed situations in which their performance was “over-valued” and they received recognition and praise that they did not believe they deserved. Sam described a situation in which a national organization invited him to receive a “Life Time” achievement award, but he did not believe that he had earned such recognition. Sam discussed his views about being recognized for “excellence”:

Awards should be earned, not just given out with little meaning. So what if I shake the President’s hand? How could I go on a talk show and talk about equality if my fame was just handed to me? I feel if I had accepted that award, it would have been the worst thing I could ever do on behalf of the disabled community....I strongly feel that if more disabled people earned a general public award with no special treatment, we would be that much closer to being an actual part of the general public. My message has always been that we should be treated as equals. It just feels to me like the disabled community is thought of as unable to truly earn things in the same way as the general public.

On occasion, the low expectations for individuals who use AAC were manifested in workplace feedback. Sam commented that sometimes individuals with disabilities are denied learning opportunities because people won’t provide appropriate feedback, noting “With every job I have, people are often too shy to tell me what I’m doing wrong. It almost feels like we want lower expectations because we don’t know how to handle criticism”.

3.4 Barriers to Employment

Participants discussed a variety of barriers to successful employment. Some, such as attitudinal barriers and educational barriers, were major obstacles to participation in the traditional job market, while others (technological barriers, and policy and funding barriers) were problematic in both the traditional job market and in self-employment.

3.4.1 Attitude barriers

Negative public attitudes toward people using AAC were cited as a primary barrier to successful employment outcomes. John commented: "The public's attitude toward us is one of the largest barriers to overcome in getting employment." Bob went on to draw an analogy between disabled persons' rights, civil rights, and the role of government intervention: "Seriously, I think we are facing the same problems that the African-Americans used to face 40 years ago, and the government passed laws."

Participants reported that they were denied opportunities to even try at a job that was deemed too difficult. Even though Ron eventually became a financially successful artist and conference presenter, he was told that he "... was too disabled with a severe communication disorder ..." to teach art.

Participants commented that they received frequent reminders that they were not viewed as meaningful participants in society. Sam wrote:

When I was growing up, people use to say to my mom 'oh it takes a very special person to take care of a disabled child.' I hated that. I was 15 and still got 'goo-gooed' at....Ever go to a restaurant? They always say something like "3 people and one wheelchair".

Carl cited this attitude as an important reason to start a business:

In a way society does push you to be self-employed because once they see you use a device, you are put in a box. People believe that they know what is the best for you because you use a communication device.

3.4.2 Educational barriers

Many of the participants had been provided with sophisticated AAC technology as students, but had not received training in the technical operation or functional use of the device. Participants expressed frustration with this lack of instructional support. Sam stated: "Giving a person a

communication device does not at all mean that we know what to say or how to respond."

Educational barriers also included inadequate and inappropriate academic programs. Most participants had not been allowed to participate in the general education curriculum, and many participants felt their time was wasted. Sam offered his view: "We were only taught half or less of what the other kids were learning, because at that time it was believed that we couldn't understand as much." As they grew older and sought employment, the participants realized the literacy skills and knowledge that they were missing. Ron wrote, "This is the time that I wish that my education was stronger instead of having teachers that didn't know what to do with me and who gave me a simple ride."

Ultimately, individuals in this study realized their own potential in a variety of ways. Sam staged a protest to get the education he felt he deserved:

As soon as I could grasp that I was not getting 'Equal' education, I tried to demand that I be allowed to take regular classes. In the 11th grade of High School I dropped out. I knew I was stuck in special education, I knew I was learning 1/2 of what everyone else was learning, and I couldn't deal with that. So I dropped out and got my GED.

Some participants commented that because of their disability, the educational personnel responsible for transition considered only a small variety of jobs. Computer programming and data entry, while frequently identified as viable employment opportunities by high school transition teams, were not always of interest to the participants in this study. Sam wrote: "In high school I was being told that I could only become a computer programmer. GAG ME! COMPUTERS ARE FUN BUT NOT THAT FUN." Carl also felt that this type of employment was not preferable: "This [data entry job] was an okay job, but sitting in front of a computer all day is not my cup of tea."

3.4.2 Technological barriers

The central role of technology as a means to communicate and complete work activities was made apparent when an equipment breakdown

occurred. John shared his thoughts: "Personally, I go nuts when equipment breaks down! Because my life seems to be one big deadline."

Speed of accessing communication devices was a primary concern for many users. Phil related his problems getting his message across in a timely fashion: "Every time someone asks me a question, I start to prepare what I want to say. Before I even get done they walk away." Bob concurred with Phil: "My biggest issue is the time that it takes to communicate." While pre-programming vocabulary was sometimes a help, participants felt that there was only so much that could be anticipated ahead of time. Inability to keep up with an oral conversation prompted Phil to declare: "You can't program a conversation."

Sam pointed out that increasing proficiency in system use is often hindered by technology upgrades: "By the time someone learns the equipment, they have to start all over with something new".

3.4.4 Policy and funding barriers

The participants discussed policy and funding barriers to employment including the complexity of reporting employment earnings and still maintaining needed medical and insurance supports. To get required home health care, Sam was required to identify himself as "sick". As he pointed out: "If everyone is thought to be 'sick' to get home health care, then of course, 'sick' people can't work.... I am not 'sick' just because I can't walk."

The participants wanted jobs with medical benefit packages through their employment, however these jobs were very difficult to obtain. Participants believed that they needed to turn down jobs that might endanger their ability to get health care. As Andrew described "...it's painful to see people with disabilities having the requirements to work a 8-5 job Monday to Friday, but are forced to turn it down because of the lack of benefits." Bob speculated as to why he thought benefits were unavailable to many individuals with disabilities. "The cold hard reality is that companies will not hire

us because of fear. They [companies] are afraid that we will jack up their insurance."

3.5 Supports to Self-Employment Activities

Individuals in this study were asked to describe significant supports to successful self-employment. From the conversations that followed, three subcategories were identified: personal characteristics, education and experience, and technology.

3.5.1 Personal characteristics

The participants reported that they were realistic about their personal strengths and abilities. As Phil commented: "I feel I can do a job just as good as the next person, but I have to work a lot harder at it." Sam described how he managed his tasks: "I know what my abilities are, and I never take on more than I can handle."

Some group members noted a combination of realistic attitude, drive, and confidence as important personal characteristics to succeed at a job. Carl described his desire to be a manager and his plan to get there:

I realize that you are not going to start out on the top of the ladder, but I feel I am qualified to start at a low management level and then work my way up... I was taught that you need to work hard to get where you want, yet you must be careful that you don't step on other people's toes.

Sam described the challenge of maintaining a positive attitude in the face of a poor reaction from others: "All we can do is have enough faith in ourselves so that the opinions of others don't matter. That's not easy."

Other participants described techniques to impress potential employers. Carl shared his technique: "I know I need to plan ahead and get accommodations ready before hand. I even negotiate pay for my helpers when I go speak at a retreat or convention." Sam described how he displayed initiative: "In the interview, I take control. I don't just pretend to be sure of myself, but I never act like I know it all."

3.5.2 Education and experience

The group emphasized education and job experiences as important supports to employment. Carl commented on the importance of formal education: "I feel I have been prepared to be self-employed by my college education."

For others "on the job" learning was seen as valuable but hard to obtain. One of Sam's current employers, for whom he did contract work, took the time to provide the feedback Sam needed to learn new skills. Sam wrote, "My boss 'kicks my butt' a lot, and sometimes I hate it. Yet because of how far I am now I wouldn't want it any other way".

3.5.3 Technology

Participants in the study identified their communication devices and systems as important supports to employment. Ron described the confidence that an effective AAC system gave him: "Once having a voice, I found out that I was unlimited and slowly things started to snowball". Bob also described the importance of his device, saying: "My Liberator is a part of me." Participants described how thoughtful use of a variety of communication techniques could help overcome communication obstacles. For example, email allowed for an individualized pace in the creation of messages, and this could sometimes be used in place of more demanding face-to-face communication. Bob wrote, "I use email a lot because it is easy... The person has my thoughts in front of him or her instantly."

3.6 Recommendations for Improved Employment Outcomes

Four major subcategories were identified following discussion of recommendations for improved employment outcomes: recommendations for individuals who use AAC, recommendations for educational institutions and schools, recommendations for AAC device manufacturers, and recommendations for government. (See Table 4 for a *Summary of Recommendations to Facilitate Self-Employment for Individuals who use AAC*).

3.6.1 Recommendations for individuals who use AAC

Recommendations for individuals who use AAC included both ideas for self-employment as well as strategies to improve access to the traditional job market. Sam suggested that individuals take "practice" jobs – that is jobs that are not necessarily a good fit for their long term goals but which can be used as learning opportunities. Sam suggested that workers "pick a skill that you want to work on, knowing that you might eventually get fired, even if it does not fit you. A variety of work experiences also helps with making contacts for future employment opportunities." Carl outlined the benefits he had experienced from efforts to network with potential employers: "Hopefully by networking I will have several offers on the table, so I can choose. It is all about networking and working hard. I have networked and it is paying off."

Being able to quickly demonstrate competence in the workplace was seen as a highly valued skill. John suggested how to establish this impression and why: "They [AAC users] must start a conversation with the interviewer right from the beginning.... you might be the first AAC user the interviewer ever saw. By starting a conversation, you will make the interviewer comfortable and show them how intelligent you are."

3.5.2 Recommendations for educational institutions and schools

The participants had experienced first hand the positive impact of education, and had numerous recommendations for teachers. Sam wrote: "Always expect the best from your students and you will never be disappointed." Carl also recommended having faith in student's ability to perform: "My message to schools is do not underestimate a child." Bob also emphasized that it is important to have high expectations, recommending to teachers "Do not cop out by saying 'oh this student will never do that, so we don't have to teach him this'".

Jim spoke of the valuable role that experienced individuals who use AAC can play for novices. He recommended a mentor program in which individuals who use AAC and have accomplished significant life goals could work and

problem-solve with younger individuals who use AAC.

3.6.3 Recommendations for manufacturers

The group also made recommendations to improve technology in the workplace for individuals who use AAC. Many of the participants wanted AAC devices that would allow them to communicate more easily with others at a distance by incorporating cell-phone or email technologies. Participants also wanted business applications such as calendars and contact lists available in their AAC devices. Sam presented a suggestion for a new approach to AAC technology, suggesting the development of a device that could recognize an individual's dysarthric speech and repeat the statement using synthesized speech. Suggestions to make AAC devices more usable in a wide variety of environments included suggestions for devices that would automatically adjust their volume level and screen brightness depending on the surrounding conditions, and devices that would be waterproof. Finally, individuals wanted devices that would better help them communicate their personality. For example, Bob wanted an easy way for the voice in his device to reflect different emotions: "the serious mode, the sarcastic mode, the funny mode, etc."

3.6.4 Recommendations for government

Some participants recommended new and stronger laws preventing discrimination and promoting education. Ron recognized the need for new programs but also the limitations: "Unfortunately, the government can do little to control morals, but it can [educate] society with public awareness programs." Sam suggested a more proactive solution: "No matter how hard we try to prove ourselves, we will only be what the Laws say we are until we change them. If we change the Laws, we change the world."

The complexity of dealing with government benefits was a frequently mentioned topic, and many participants wanted universal health care, both so that their medical costs would not serve as a deterrent to a potential employer and so that they would not have to worry about the impact of earned

income on government benefits. Sam wanted more financial control over the funds used for attendant care, and the right to personally hire and fire attendants:

It would be much better if we could just all deal directly with the State...if we got rid of all of these "do nothing" agencies, the pay (for care providers) would go up. We would get much better help, and maybe it would effect our ability to work...

4. Discussion

For the individuals in this study, self-employment provided a measure of income, the knowledge that they were active participants in society, and, for many, a chance to help others. Four of the seven were involved in "community building" activities (e.g. advocacy work, youth ministry). For all of the participants, their self-employment activities were valued not only for the benefits that they brought the individual worker, but for their potential impact on society and societal attitudes.

Self-employment brings its own challenges, including the potential of social isolation [5] and the challenges of managing personal finances and coordinating government benefits [7]. There also are benefits to employment in community based settings (e.g., social interaction, public recognition) that may be more difficult to obtain while working from a home-based office [13].

These challenges notwithstanding, self-employment allowed these individuals to demonstrate skills and talents that often were not valued in traditional office-based competitive employment situations. The participants in this study frequently described the discrimination they faced in their efforts to be employed in "mainstream" society. Self-employment provided these individuals with an opportunity to set their own rules and standards, and to be able to work to meet their own goals.

Despite considerable effort to be self-supporting, all of these individuals received some type of financial assistance from the government. The fact that these businesses were typically not the primary means of financial support should not result in the interpretation that they were not successful.

As reported by Hagner and Davies [5] these small businesses provided a sense of identity for individuals with severe disabilities, and a supplemental income that enabled them to participate in important life events like getting married or obtaining their own apartment.

For individuals with severe disabilities, the option of self-employment may become even more important during the coming years. The Federal Government, traditionally a good employment opportunity for individuals facing discrimination in the private sector [17], reduced its workforce by 19% between 1985 and 2000 [3]. At the same time, the percentage of temporary (i.e., nonpermanent or less than fulltime) jobs grew to make up approximately 30% of the US workforce [23]. For individuals with severe disabilities, the compensation package offered in their part-time or temporary positions is rarely sufficient to meet the living needs of individuals with significant medical or care expenses [7]. The model of self-employment activities as a supplement to government assistance may be a useful option for individuals who use AAC.

While many services and supports need to be in place in order for employment to be a success, the vocational rehabilitation counselor can provide support in three key areas to individuals who use AAC and are considering self-employment as a long-term goal. First, while the individual is in school, the counselor should advocate for an appropriately challenging educational program. While educational goals need to be set on an individual basis, many of the participants spoke of the importance of strong reading and writing skills. Many of the individuals were involved in jobs that required the use of computer technology, and strong literacy skills were key. Second, vocational rehabilitation personnel can offer an important work-place perspective on the individual's communication skills and priorities for intervention. Different job activities will require different communication skills, however past research has documented the importance of being able to communicate as clearly and as quickly as possible, and to make use of appropriate workplace social skills [13]. Third, the vocational rehabilitation counselor should help identify a wide variety of part-

time or "work-experience" jobs while the individual who uses AAC is still in school. The work experiences will help the individual to develop both "formal" job skills (e.g., working with a database) as well as "informal" skills (e.g., learning to manage personal care services in the workplace). Work-experience activities also give direction to the educational program by helping to identify individual areas of strength and of concern, and assist individuals in developing a network of potential employers that may be helpful when the individual is seeking long-term employment.

5. Conclusion

While self-employment may only be able to provide full financial support for a small number of individuals, it can play an important role in augmenting government support for many others. Like the individuals described here, self-employment may be just one part of a constellation of activities, including traditional work activities and community-building volunteer activities. These employment activities allow people who use AAC to feel both some measure of financial independence as well as additional pride in their employment activities. As one of the participants commented, in describing his emotions when he received his first pay, "I feel human for the first time in my life".

Society should recognize a wide variety of achievements, not just those that result in the generation of income [17]. At the same time, as a society, we need to work to ensure that individuals with severe disabilities have access to the supports and services they need to pursue desired outcomes such as self-employment. As Rizzo [18] noted, the capacity of an individual to sustain employment is often more a factor of the supports provided rather than the disability. Given the importance of self-employment in the lives of the people described here, the need for the appropriate provision of supports is clear.

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References

- [1] Atanasoff, L. M., McNaughton, D., Wolfe, P., and Light, J. (1998). Communication demands of university settings for students using augmentative and alternative communication. *The Journal of Postsecondary Education and Disability*, 13 (3), 32-47.
- [2] Beukelman, D. & Mirenda, P. (2005). *Augmentative & Alternative Communication: Supporting Children & Adults With Complex Communication Needs*. Baltimore, MD: Brookes Publishing co.
- [3] Congressional Budget Office (2001). *Changes in Federal Civilian Employment: An Update (2001)*. [On-Line] Available <http://www.cbo.gov/showdoc.cfm?index=2864&sequence=0>
- [4] Greenwood, R., Johnson, V.A., & Schriener, K.F. (1988). Employer perspectives on employment-rehabilitation partnerships. *Journal of Applied Rehabilitation Counseling*, 19, 8-12.
- [5] Hagner, D. & Davies, D. (2002). "Doing my own thing": Supported self-employment for individuals with cognitive disabilities. *Journal of Vocational Rehabilitation*, 17, 65-74.
- [6] Kent-Walsh, J., & Light, J. (2003). General education teachers' experiences with inclusion of students who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 19, 104-124.
- [7] Krezman, C. (1994). How much does getting a job cost? In R.V. Conti & C. Jenkins-Odoriso (ed.), *The Second Annual Pittsburgh Employment Conference for Augmented Communicators*, 2, (pp.61-66). Pittsburgh, PA: SHOUT Press.
- [8] Landis, J. & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33, 159-174.
- [9] Light, J., Stoltz, B., & McNaughton, D. (1996). Community-based employment: experiences of adults who use AAC. *Augmentative and Alternative Communication*, 12, 215-228.
- [10] Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications.
- [11] Matas, J., Mathy-Laikko, P., Beukelman, D., & Legresley, K. (1985). Identifying the non-speaking population: A demographic study. *Augmentative and Alternative Communication*, 1, 17-31.
- [12] McNaughton, D., & Bryen, D. (2002). Enhancing Participation in Employment Through AAC Technologies. *Assistive Technology*, 14, 58-70
- [13] McNaughton, D., Light, J., & Arnold, K.B. (2002). "Getting your 'wheel' in the door": The successful full-time employment experiences of individuals with cerebral palsy who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 18, 59-76.
- [14] McNaughton, D., Light, J., & Groszyk, L. (2001). "Don't give up": The employment experiences of adults with amyotrophic lateral sclerosis who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 17, 179-195.

- [15] McNaughton, D., Light, J., & Gulla, S. (2003). Opening up a "Whole new world": Employer and co-worker perspectives on working with individuals who use augmentative and alternative communication. *Augmentative and Alternative Communication, 19*, 235-253.
- [16] Mirenda, P. (1996). Sheltered employment and augmentative communication: An oxymoron. *Augmentative and Alternative Communication, 12*, 193-197.
- [17] Rifkin, J. (1995). *The End of Work*. New York: Putnam
- [18] Rizzo, D. C. (2002). With a little help from my friends: Supported self-employment for people with severe disabilities, *Journal of Vocational Rehabilitation, 17*, 97-105.
- [19] Seekins, T. (1996). Rural economic development and vocational rehabilitation: Lesons from analyses of self-employment as a vocational outcome. In L.G. Perlman & C.E. Hansen (Eds.) *The entrepreneur with a disability: Self-employment as a vocational goal. A report on the 19th Mary E. Switzer Memorial Seminar*. Alexandria, VA: National Rehabilitation Association.
- [20] Staehly, J. (2000). The Communication Dance. In M. Fried-Oken & H. Bersani (Eds.), *Speaking up and spelling it out*. Baltimore, MD: Paul H. Brookes, p. 1-12.
- [21] Suen, H. K., & Ary, D. (1989). *Analyzing quantitative behavioral observation data*. Hillsdale, NJ: Lawrence Erlbaum.
- [22] U.S. Census Bureau (1997). *Americans with Disabilities: 1997*. [On-Line]. Available <http://www.census.gov/hhes/www/disable/sipp/disab97/ds97t4.html>.
- [23] U.S. Department of Labor (1999). *Report of the Working Group on the Benefit Implications of the Growth of a Contingent Workforce*. [On-Line]. Available <http://www.dol.gov/ebsa/publications/contrpt.htm>
- [24] Vaughn, S., Schumm, J.S., & Sinagub, J. (1996). *Focus group interviews in education and psychology*. Thousand Oaks, CA: Sage Publications.

APPENDIX A Topics and Questions Posted to the Discussion by the Moderator

Topic	Question
Welcome! Please click here and say "Hi!"	<p>Welcome! Thank you for joining our discussion! Before proceeding to our first topic, could you please post a message saying "Hello" and, for the fun of it, please tell us something about local news that is important to you. It could be something about a recent holiday or local events, or even just the weather. This will give you a chance to practice using this Discussion Site (and help us imagine where you are when you post to this Site!)</p>
Benefits	<p>What are some of the good things about having a job? Clearly having a job involves a lot of hard work, and not everyone makes the same decision. If someone were to ask why you have chosen to work so hard to have a job (or, for some of you, a number of jobs), what would you say?</p>
Finding a job	<p>As some of you may have guessed, you are a unique group! You are all individuals who, in one way or another, are self-employed. You are writers, musicians, artists, ministers. You are not working 9-5 jobs in an office.</p> <p>I am interested in how you made the decision to be self-employed.</p> <p>Did you try the "9-5" world and decide it wasn't for you?</p> <p>Do you think you faced special challenges in finding a "conventional" job because you are an AAC user, and being self-employed was your best way to make an income?</p> <p>Did you decide to be self-employed because the activity you love most (e.g., art) is not something that most businesses want to hire?</p>
What the government should do	<p>In a nutshell, how did you come to be self-employed?</p> <p>A number of you have mentioned problems you have faced in seeking employment: Bob mentioned the concern of some employers about health insurance rates, others have mentioned that some employers do not see beyond the disability.</p> <p>What do you think the government's role should be in addressing these problems?</p> <p>Are these "people" problems that government cannot change, or is there legislation that could improve the job prospects of people with disabilities?</p> <p>If you could "run Washington for a day" (or a year), what would you do?</p>
Communication and AAC Technology	<p>A number of you have talked about the importance of AAC technology, and a number of you have also mentioned that you</p>

Supports	<p>are sometimes frustrated with this technology (e.g., problems with the telephone, problems connecting up to computers). One of the groups that is interested in what you have to say is Rehab Engineers who are involved in designing the "next generation of AAC" devices. What have been your experiences with AAC technology in working with other people? What has been positive about the AAC technology that you use? What has been a problem with the AAC technology that you use?</p> <p>Other individuals who use AAC and their family members will read about the results of this research, and many will be interested in starting businesses from home and becoming self-employed. I am interested in what is needed to make that happen. A number of important supports have been mentioned so far - the support of family members, the use of assistive technology, and reliable personal care attendants</p>
Message to schools	<p>What have been your experiences? What are the supports that have been important to you in being self-employed?</p> <p>One of the goals of this project is to provide individuals who use AAC, their parents, and teachers, with information on how individuals who use AAC can prepare for employment while they are still in school. Already, some of you (Carl and Sam) have mentioned that your schools routed you into boring data-entry jobs, and failed to offer programs that were academically challenging.</p> <p>I am hoping that at least some of the time there was a mix of the "good" with the "bad". Looking back, what were some of the things that happened in school that helped you get ready for the "world of work"? Was there anything or anyone in your school years that was particularly helpful?</p> <p>Also, was there something that you wanted at school but did not get? Looking back now, was there a way that school could have better prepared you to find and keep a job, and/or to pursue your current self-employment projects? What would you like the teachers of tomorrow to know or do? While clearly there are a lot of attitudes that need to change, I am also interested in specific strategies that you think might be useful (.e.g., providing individuals who use AAC with legal training so they can advocate for their rights in the special education system).</p>
Message to technology developers	<p>As you have discussed augmentative communication technologies you have referred to features that you like in augmentative communication technologies (e.g., fast, large digital memories) , and features that you do not like (slow, short battery life).</p> <p>What would be the features of an ideal augmentative communication device? Another part of this research project is a group of engineers who want to hear from technology users what</p>

the next generation of technology should include. We would all be sincerely interested in your ideas on this topic. Again, please don't be shy about coming up with "far-fetched" ideas, 5 years ago no-one knew the WWW would look like this.

Also, don't think you have to figure out HOW to do it, just say WHAT YOU WANT. For example, if what you want is a device that can work for 24 hours at a time, you don't need to say "I want a device that can plug into an electric wheelchair battery", just say you want a device that can work for 24 hours at a time!

Many of you were at the Pittsburgh Employment conference last summer and you heard the ideas of individuals who use AAC there: daily calendars, cell phones, pagers, WWW link-ups, and (I think this was a joke) a home entertainment system. I would encourage you to "think big", as Bob did when he said he wanted a "mind meld". What is on your "wish list"?

Barriers to developing your
business

What are some of the things that make it hard to get a job or develop your business?

We have spoken extensively about the problem of people's attitudes, are there other factors that also provide challenges? Are there government programs that have made it hard for you to get a job or develop your business?? transportation? Computer breakdowns? Problems with OVR? I would be interested in hearing about some of the reasons that it is sometimes hard to get a job or develop your business.

APPENDIX B: Operational Definitions of Coding Themes

1. *Description of Employment Activities* - Comment that provides information about employment activities, but does not include benefits/ reasons for employment, negative impacts, barriers, or supports related to employment (e.g., "my duties included").
2. *Benefits of Self-Employment* - Positive outcomes resulting from engagement in employment activities, including social, financial, familial, personal, psychological, or physical gains. Motivational factors or reasons for participating in employment activities, including negative effects of unemployment.
3. *Negative Impact of Self-Employment* - Negative experiences (including social, financial, familial, personal, psychological, or physical) resulting from engagement in employment.
4. *Barriers to Employment* - Any person, organization, situation, action, or device that impedes an individual's ability to obtain and maintain a job. Barriers can include policies, practices, attitudes, knowledge, skill, education, preparation, information dissemination, access, or physical/medical conditions.
5. *Supports to Self-Employment* - Any person, organization, situation, action, or device (including educational) that enables or assists an individual to obtain and maintain a job.
6. *Recommendations* - Suggestions regarding ways of overcoming barriers to employment based upon the participants' personal experiences and ideas. Includes recommendations to persons with cerebral palsy and their families, employers, co-workers, policy makers, service providers, rehabilitation professionals, and technology developers.
7. *Unrelated Statement* - Comment or question that is unrelated to cerebral palsy and not directly related to employment (e.g., "Go Nittany Lions!").

Table 1: Demographic Characteristics of the Participants

Variable	Participant						
	Andrew	John	Carl	Sam	Phil	Bob	Ron
Gender	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>
Age	22	49	26	35	28	44	53
Disability	CP ⁸	CP	CP	CP, VI ⁹ corrected	CP	CP, VI, uses display magnifier	CP, VI corrected, HI ¹⁰ corrected
Mobility	Power wheelchair	Power wheelchair	Power wheelchair	Power wheelchair	Manual wheelchair	Power wheelchair	Power wheelchair
Education	Some college	Bachelor's degree	Bachelor's degree	High School (GED)	High school diploma	Bachelor's degree, some graduate coursework	Some college
Means of communication	Liberator	Liberator	Dynavox 3100, Speech,	Vanguard, speech	E-tran board with letters,	Liberator	Dynavox 3100
Length of use of current AAC system	8 years	12 years	2 months	2.5 years	25 years	8 years	10 years
Writing system	Standard keyboard	Standard keyboard	Adapted keyboard (Intellikeys)	Portable AAC device	On-screen keyboard	Standard keyboard	Portable AAC device
Access techniques	Finger	Finger	Left big toe to type and a trackball	Finger	Eyegaze, HeadMouse	Headstick	Headstick

⁸ Cerebral palsy

⁹ Vision impairment

¹⁰ Hearing impairment

Table 2

Coding Themes, Subthemes, and Examples of Issues Discussed by Participants

Coding Themes	Sub-themes	Examples of Issues discussed by Participants
Benefits of self-employment	Financial benefits	<ul style="list-style-type: none"> – Providing for others – Being financially independent
	Enjoyment of work activities	<ul style="list-style-type: none"> – Being with others – Being active – Flexibility of self-employment
	Fulfillment of personal expectations	<ul style="list-style-type: none"> – Contributing to society – Meeting job challenges – Exceeding expectations of others
	Societal change	<ul style="list-style-type: none"> – Demonstrating competence of individual who uses AAC
Negative impacts of self-employment	Financial impact	<ul style="list-style-type: none"> – Reductions in government benefits
	Societal prejudice	<ul style="list-style-type: none"> – Work is “under-valued” – Work is “over-valued”
Barriers to employment	Attitude barriers	<ul style="list-style-type: none"> – Being denied opportunities to participate
	Educational barriers	<ul style="list-style-type: none"> – Lack of instruction in use of AAC – Low expectations of teachers – Limited options considered in vocational planning
	Technological barriers	<ul style="list-style-type: none"> – Technology break-downs – Needing to be able to communicate quickly – Technology upgrades

	Policy and funding barriers	<ul style="list-style-type: none"> – Government support programs (e.g., SSI) complicated – Need to coordinate health insurance, home health care – Lack of medical benefits in entry-level positions
Supports to self-employment	Personal characteristics	<ul style="list-style-type: none"> – Knowledge of personal strengths and goals – Interest in demonstrating competence – Ability to plan for needs
	Education and experience	<ul style="list-style-type: none"> – Strong formal education – On the job learning
	Technology	<ul style="list-style-type: none"> – Competence in device use – Coordinated use of different communication technologies (e.g., email).

Table 3 Employment Characteristics of the Participants

Variable	Participant						
	Andrew	John	Carl	Sam	Phil	Bob	Ron
Job activities	Web site development, advocacy	Printing, office work, software consulting	Freelance speaker, Assistant Youth Pastor, Chairman of nonprofit organization	Musician, software consultant	Pottery maker	Freelance journalist, public speaker on disability rights	Artist, religious/motivational speaker, author, AAC Consultant
Time at job (yrs)	1.6	25	3	10	5	5	30
Prior employment	None	Copying services at a larger manufacturer	Data entry	Newspaper reporter, singer	Newsletter editor	Freelance magazine writer	None
Main Income/ Supplement. To SSI	Supplement	Supplement	Supplement	Supplement	Supplement	Supplement	Main
Work Hours/ Week	10-20	10	Youth pastor 7 hours; chairman 5-10; freelance speaker 5-10	35-40	10-20	10	20
PCA hrs/wk	15-22	Family provides care	28	35	Family provides care	3	70
Compensation ¹¹	Declined to respond	Minimum wage	More than minimum wage	More than minimum wage	Minimum wage or less	More than minimum wage	More than minimum wage

¹¹ Compensation received for total hours worked

Table 4

Summary of recommendations to facilitate self-employment for individuals who use AAC

Audience	Recommended Actions
1. Individuals who use AAC	<ul style="list-style-type: none"> - Take "practice" jobs - Network with co-workers and future employers - Demonstrate competence - Learn social interaction skills
2. Educators	<ul style="list-style-type: none"> - Communicate high expectations - Listen to students - Set up a mentor program
3. Technology developers	<ul style="list-style-type: none"> - Add cellphone capabilities to AAC devices - add business applications (e.g., calendars, contact databases) to AAC devices - Develop computer "translator" to interpret dysarthric speech - Add capability of automatic device adjustment to changing noise and lighting conditions to AAC device - Manufacture more durable, water-proof devices - Provide synthesized speech that communicates personality and emotion
4. Policy makers	<ul style="list-style-type: none"> - Create legislation to fight discrimination - Provide economic supports (e.g., universal health care, minimum annual income) to promote independence - Give individuals with disabilities control over personal care attendant funding