

# **“Don’t Give Up”: Employment Experiences of Individuals with Amyotrophic Lateral Sclerosis Who Use Augmentative and Alternative Communication**

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**A focus group discussion was conducted on the Internet to investigate the employment experiences of five individuals with amyotrophic lateral sclerosis (ALS) who required augmentative and alternative communication (AAC). Information was gathered in the following areas: (a) the benefits of and reasons for continuing employment, (b) the negative impacts of employment, (c) the barriers to continued employment, (d) the supports required for successful employment outcomes, and (e) recommendations proposed for employers, rehabilitation professionals, manufacturers of assistive technology, the government, and individuals with ALS themselves to facilitate employment. Factors described as important to the participants’ continued employment included the nature of employment activities, necessary supports to employment activities (e.g., the availability of information and services), and access to appropriate communication systems.**

**KEY WORDS:** amyotrophic lateral sclerosis (ALS), assistive technology, augmentative and alternative communication (AAC), degenerative neurologic disorder, employment, focus group, Internet

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The onset of a degenerative neurologic disorder such as amyotrophic lateral sclerosis (ALS) impacts every aspect of an individual’s life (Mathy, Yorkston, & Gutman, 2000). Because the progression of ALS varies across individuals, in terms of both the speed of decline and the areas of involvement, individuals with ALS face serious challenges in planning their personal and professional lives (Beresford, 1995).

For individuals with ALS, as with many in our society, employment plays a key role in defining socioeconomic status, personal self-image, and the quality of life generally (Blackstone, 1993; McCarthy, 1986). Individuals with degenerative neurologic disorders such as ALS, however, may face special challenges in maintaining employment. A diagnosis of ALS is often closely followed by the loss of employment status (Fried-Oken, 1993; Young & McNicoll, 1998).

To date, only Fried-Oken (1993) has examined employment issues for individuals with acquired degenerative neurologic disorders. In reporting the results of a written survey conducted with six individuals with ALS who used AAC, Fried-Oken (1993) suggested that there are at least four possible reasons why individuals with acquired degenerative muscular diseases frequently do not maintain employment after diagnosis: (a) the severe physical impact of the illness, (b) the challenges of learning and using communication

technology, (c) negative societal attitudes, and (d) the late onset of the disease (since the mean age of onset is 56, many individuals of this age may choose early retirement rather than attempting to continue working).

Fried-Oken’s (1993) investigation provided documentation of successful employment outcomes for individuals with ALS, thus illustrating that the continuation of employment status is a possibility for individuals within this population. However, the specific barriers encountered by individuals with ALS in attempts to maintain employment have not yet been identified, nor has it been determined how to improve employment outcomes for individuals who have been diagnosed with ALS and who require AAC.

This study investigated the experiences of five individuals with ALS who required AAC, including the types of employment activities in which they were engaged and their use of AAC systems. More specifically, the study investigated (a) the benefits of and reasons for continuing employment, (b) the negative impacts of employment, (c) the barriers to continued employment, (d) the supports required for successful employment outcomes, and (e) recommendations proposed for employers, rehabilitation professionals, manufacturers of assistive technology, the government, and individuals with ALS themselves to overcome barriers to employment.

## METHOD

### Design

The study employed a qualitative research design involving the use of a focus group. Traditionally, focus group participants are required to gather for discussion in one physical setting for a period of 1 to 3 hours (Payne, 1989; Vaughn, Schumm, & Sinagub, 1996). Given the low incidence of the target population (i.e., individuals with ALS who require AAC and who are successfully employed), it would not have been possible to conduct a focus group in a conventional manner without requesting participants to travel a significant distance to participate in the discussion. Therefore, the focus group used in this study was conducted via the Internet.

Using the Internet decreased the physical demands on the participants as it allowed individuals from any location to join the discussion from their homes or offices without having to travel. In addition, there was no designated time that the focus group convened. Rather, participants could contribute to the discussions during times that were convenient for them and at a pace that was individually appropriate with respect to fatigue.

### Participants

#### Criteria for Participation

The criteria for participant selection were as follows: individuals must have (a) been diagnosed with ALS and must have required AAC, (b) been employed for at least 3 months while having ALS and have required the use of AAC during this time (employment at the time of the study was not required), (c) worked a minimum of 10 hours per week in community-based employment within the past 12 months, and (d) viewed their employment experiences as successful.

#### Recruitment of Participants

The recruitment of participants was conducted through various means: (a) a description of the research project was posted on the *ALS Digest*<sup>1</sup> located on the Internet, inviting individuals with ALS who were employed to participate; (b) the archives of the *ALS Digest* were reviewed, and individuals who had previously identified themselves as being employed were contacted directly; (c) the 14 Muscular Dystrophy Association/Amyotrophic Lateral Sclerosis (MDA/ALS) Research and Medical Care Centers throughout the country were contacted and notified of the research

project; (d) nominations of participants were solicited from researchers and clinicians within the field of AAC through a general electronic (e-) mail message sent out to all members of the United States Society for Augmentative and Alternative Communication (USSAAC); and (e) as participants were identified, they were asked to share information about the project with other individuals with ALS whom they knew, as appropriate.

#### Description of Participants

A total of seven individuals with ALS who used AAC were involved in the focus group discussion. This article focuses exclusively on the comments made by five individuals who used AAC while employed and does not include comments made by the two individuals with ALS who were using AAC at the time of the study but had not used AAC while employed. For the remainder of this article, the term "participant" refers to the five individuals with ALS who used AAC while employed.

Thus, five participants were involved in the study, three women and two men, ranging in age from 50 to 57 years. The participants had been diagnosed with ALS between 1 and 8 years prior to the study and had been using AAC for a period of between 6 months and 5 years. As is evident in Table 1, the participants were engaged in a variety of employment activities. See Table 1 for a summary of the participants' demographic information.

### Materials

ConferWeb 2.1,<sup>2</sup> a "guestbook" software program, was used for the focus group discussion on the Internet. ConferWeb 2.1 is a password-protected Macintosh-based program that 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 at which participants can post discussion comments on a particular topic. Individuals can read postings from other participants and post entries to the discussion site in a designated "comment" area.

### Procedures

Once participants indicated their willingness and consent to participate, they were sent a brief questionnaire through electronic mail to gather background information regarding their current employment activities, previous employment, and use of AAC systems. They were asked to complete the questionnaire and to return their responses via e-mail. The focus group

<sup>1</sup>The *ALS Digest* is an e-mail newsletter about ALS published on a weekly basis. Backcopies and information on how to join are available at [www.glnicholas.com/](http://www.glnicholas.com/).

<sup>2</sup>Additional information on ConferWeb is available at <http://www.caup.washington.edu/software/conferweb/>.

TABLE 1: Demographic Data for the Participants

	<i>Blake</i>	<i>Doug</i>	<i>Frank</i>	<i>Julia</i>	<i>Kayla</i>
Age	*	53	50	57	52
Diagnosis (time prior to study; yr)	1	1	5	2.5	8
Type of ALS diagnosed	Bulbar	"Atypical"	Spinal	Bulbar	*
Motor/physical status	Independent ambulation; some paresis in extremities	Wheelchair; upper extremity paresis	Wheelchair; upper extremity paralysis	Independent ambulation; extremity paresis	Wheelchair and ventilator dependent
Current activities	Pharmacist	School administrator	Corporate contract negotiator	Volunteer for local ALS organization	Writer for two newspapers
Length of engagement in current activities	5 yr	2.5 yr	25 yr	8 mo	5 yr
Employment activities prior to ALS diagnosis	Pharmacist	School administrator	Corporate contract negotiator	Account director for marketing agency	Business magazine editor and writer
Use of AAC systems	Link <sup>†</sup> message board, TTY, <sup>§</sup> gestures	SpeakEasy, <sup>‡</sup> Madenta ScreenDoors onscreen keyboard <sup>  </sup>	Madenta ScreenDoors onscreen keyboard, word prediction software, Gus! Dwell Cursor <sup>#</sup>	Link, memo pad	E-Tran alphabet board, <sup>**</sup> EZ Keys, <sup>††</sup> P-Switch <sup>‡‡</sup> to activate bell for attention
Access method	Direct selection	Direct selection	HeadMouse <sup>§§</sup>	Direct selection	Eye-gaze alphabet board, infrared switch <sup>   </sup> at corner of mouth
Length of use of AAC	6 mo	1 yr	4 yr	1.5 yr	5 yr

\*Information that was not provided by participants.

<sup>†</sup>The Link™ is a portable keyboard device that has voice output capabilities, featuring DECTalk synthesized speech. It has a small display that presents typed messages. The Link can be interfaced with a computer for basic word processing and requires direct selection of keys. Additional information is available from Assistive Technology, Inc., 850 Boylston St. #317, Chestnut Hill, MA 02467, USA, and at [www.assistivetech.com](http://www.assistivetech.com).

<sup>§</sup>A teletype (TTY) is a text telephone, which provides an individual with a means of communicating over the telephone by typing messages rather than using speech. Additional information is available from Ultratec, Inc., 450 Science Dr., Madison, WI 53711, USA, and at [www.ultratec.com](http://www.ultratec.com).

<sup>‡</sup>SpeakEasy is a computer software program that converts typewritten text into synthesized speech and has the ability to retrieve prestored audio messages. Additional information is available at [www.speakeasily.com](http://www.speakeasily.com).

<sup>||</sup>Madenta ScreenDoors onscreen keyboard provides an alternative means of accessing the keyboard through mouse movements and clicks as the keyboard is represented on the computer screen. Additional information is available from Madenta Communications, Inc., 9411A-20 Ave., Edmonton, AB T6N 1E5, Canada, and at [www.madenta.com](http://www.madenta.com).

<sup>#</sup>The Gus! Dwell Cursor provides a means of activating mouse button clicks. Additional information is available from Gus Communications, Inc., 1006 Lonetree Court, Bellingham, WA 98226-3167, USA, and at [www.gusinc.com](http://www.gusinc.com).

<sup>\*\*</sup>An E-Tran board is a large, square, plexiglass light-technology system that allows an individual to indicate selection of letters via eye gaze.

<sup>††</sup>EZ Keys is a software program that provides computer access and environmental control. It has a variety of features, including voice output, word prediction, mouse emulation, and adaptive switch accessing capacities. Additional information is available from Words+, 1220 West Ave. J, Lancaster, CA 93534-2902, USA, and at [www.words-plus.com](http://www.words-plus.com).

<sup>‡‡</sup>A P-Switch functions by using sensors to detect muscle movements, allowing control and activation of various equipment. Additional information is available from Prentke Romich Company, 1022 Heyl Road, Wooster, OH 44691, USA, and at [www.prentrom.com](http://www.prentrom.com).

<sup>§§</sup>The HeadMouse sensor replaces the standard desktop computer mouse and translates the movements of a user's head into directly proportional movements of the computer mouse pointer.

Additional information is available from Origin Instruments Corporation, 854 Greenview Drive, Grand Prairie, TX 75050, USA, and at [www.orin.com/access/headmouse/](http://www.orin.com/access/headmouse/).

<sup>|||</sup>An infrared switch is a remote control method of accessing a computer using an infrared receiver and transmitter. Additional information is available from Words+, 1220 West Ave. J, Lancaster, CA 93534-2902, USA, and at [www.words-plus.com](http://www.words-plus.com).

discussion began after all of the participants completed and returned their questionnaires.

An e-mail message was sent to each participant providing instructions on how to log onto the Confer-

Web discussion site. As part of the instructional activities, the participants were asked to post an introductory message to demonstrate their ability to post messages to the site.

The procedures for the focus group discussion were based on the best practices recommended by Vaughn et al. (1996). These practices were adapted as required to meet the unique characteristics of an Internet-based focus group discussion (Table 2).

The first author served as the moderator of the focus group and was responsible for presenting the discussion topics, encouraging dialogue, and regulating the discussions as needed (i.e., redirecting the discussions, requesting participation). Periodically over the course of the focus group discussion, the moderator posted new questions and topics (see Appendix A for questions posted to the site by the moderator). The topics for the questions (e.g., "barriers to employment") were identified before the focus groups began; the specific wording for the questions was developed as each question was introduced so as to incorporate relevant comments posted by participants. The discussions were not linear; rather, the discussion of different topics overlapped (e.g., on a single visit to the site, participants might post to three different topics).

The participants were asked to visit the Internet site at least three times each week and respond to the questions posted by the moderator and to the contributions of the other members of the focus group. The focus group continued for a 6-week period. During this time, the participants posted 93 comments, a total of 10,560 words, to 14 discussion topics.<sup>3</sup>

### Data Analysis

Prior to the data analysis process, data were saved from the Web site to a word-processing document. Analysis procedures then followed a five-step process, adapted from Yin (1994) and Vaughn et al. (1996).

In Step 1, "Unitizing the Data," the information from the print and interview questionnaires was "unitized." The text was broken up into "the smallest amount of information that was informative by itself" (Vaughn et al., 1996, p. 106). These units were typically a single phrase or sentence (e.g., "I would tell anyone with ALS to maintain a positive attitude").

In Step 2, "Coding the Data," the units were then reviewed and organized into themes on the basis of topic and content. During this process, operational definitions for the sorting of information into themes were developed by the third author. The units of information coded for a particular theme (e.g., benefits of employment) were reviewed to identify the existence of sub-themes (e.g., need to avoid preoccupation with ALS).

In Step 3, "Negotiating Agreement," the researchers used the operational definitions to code

the data for samples of text drawn from the participants. The researchers met to review areas of agreement and disagreement, to create new themes and subtheme titles for information that was not addressed by the original themes identified, and to adjust theme titles and operational definitions, as necessary (see Appendix B for the final operational definitions of the coding themes). These operational definitions were then used by the third author to code all of the data.

In Step 4, "Calculating Agreement," a graduate student in the Department of Communication Disorders was introduced to the operational definitions used for the coding of themes. As part of a training activity, the graduate student coded and received feedback on a small number of text samples. The graduate student then independently reviewed and coded 20% of the data. Inter-rater reliability indicated 88% agreement

TABLE 2: Adaptations of Focus Group Discussion Procedures for the Internet

<i>Traditional Moderator Activities*</i>	<i>Internet Adaptation</i>
Introduce participants	The moderator, in a private e-mail message, asked each participant for a brief self-descriptive passage. He then used the information provided by the participants to create a password-protected Web site where participants could read about one another.
Open discussion and introduce topics	The moderator began the discussion and introduced new topics by creating new discussion topic pages at the Web site (see Appendix A for questions posted to the discussion by the principal investigator).
Create and maintain comfortable environment	The moderator thanked participants for their contributions, both publicly at the site and in private e-mail messages.
Focus attention on relevant topics	The moderator posted follow-up questions at the Web site to focus attention on major topics of interest. New topics were introduced once a majority of participants had posted to a topic. The moderator sent private e-mail messages to specific participants to solicit participation on particular topics, as necessary.
End focus group and summarize discussion	The participants were sent a summary of the discussion and were asked if the summary reflected their view of the discussion and if they had anything to add.

<sup>3</sup>The moderator posted eight questions (including the "Welcome" message). The participants posted six new topics of their own, typically questions about specific technologies mentioned by participants.

\*As suggested by Vaughn et al., 1996.

(the number of agreements divided by the number of agreements, disagreements, and omissions).

In Step 5, "Confirming the Summary with the Participants," each participant was sent a copy of the results as summarized by the researchers via e-mail. Participants were asked to comment on the accuracy and presentation of the findings. All five participants replied to the result summaries and verified that they accurately reflected their contributions to the focus group discussion.

The final coding themes were (a) benefits of employment or reasons for engaging in employment activities, (b) negative impact of being employed, (c) barriers to employment, (d) supports to employment, (e) recommendations to overcome barriers to employment, (f) description of employment activities, (g) issues specific to ALS, and (h) general statements unrelated to either employment or ALS issues (see Appendix B for operational definitions of coding themes).

## RESULTS

This section presents the findings of the study and discusses these findings as they relate to each of the five main coding themes. Tables 3 and 4 provide a summary of the themes, subthemes, and examples of specific issues discussed by the participants and a summary of recommendations to employers, rehabilitation professionals, manufacturers of assistive technology, the government, and individuals with ALS themselves to facilitate employment.

### Benefits of Employment and Reasons for Being Employed

Four subthemes related to the benefits of employment were expressed by the participants: (a) the need for productive activities, (b) personal identification with work activities, (c) positive experiences in the workplace, and (d) practical benefits of employment.

#### *Need for Productive Activity*

Three specific issues related to productivity were discussed, including the need to be productive to avoid dwelling on ALS. As Doug noted, "My motivation to continue to work and be productive has a couple of 'drivers' . . . [one of them is] being involved in productive activity to avoid dwelling on myself and my health. Computer solitaire and hours of CNN and the History Channel just don't appeal." Participants also spoke of the need to feel productive, to feel that they were making a contribution to the workplace. As Julia commented, "I felt I still had a lot to contribute and could not face an abrupt transition to retirement."

Participants also spoke of the need to be productive to enhance their mental and physical well-being. Kayla described her experiences this way:

The day I started writing again, professionally, my nurse was scared to death. Suddenly, my pulse was racing, and my blood pressure was up. For the first year I was on the vent[ilator], all I did was watch TV and, as the others have said, that gets old fast. I never thought that I'd write again because I couldn't use my hands or speak. Being able to write again has given my life purpose, a reason to get up and get going every day.

#### *Personal Identification with Employment Activity*

The second subtheme involved continuing employment as a result of personally identifying with one's occupation. As Blake explained, "I've always identified with my profession . . . I am a pharmacist." Julia discussed her job as an integral part of who she is: "It is very hard to give [your job] up as it is more than work: it is a lifestyle, it is a part of one's identity. . ."

#### *Positive Experiences in the Workplace*

The third subtheme focused on the participant's continued engagement in employment activities owing to positive experiences in the workplace. Here, participants described the importance of being in a supportive and appreciative environment. Doug wrote the following description of the support he received as a school administrator:

The staff, faculty, and students have rallied round us from the outset of this experience in such a supportive way that I cannot imagine not being as involved for as long as possible. I am still paid my salary, provided with housing and am carried on medical insurance. I will serve in any capacity I am able for these folks.

Frank also spoke of his loyalty to those who were supporting him:

Luckily, 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.

Participants also spoke of the significance of the social aspects of the workplace. Julia addressed this issue directly, writing, "Your job is more than work . . . it is a place to be with friends and be stimulated."

#### *Practical Benefits of Employment*

The two specific issues that emerged from this subtheme involved being employed owing to financial

TABLE 3: Coding Themes, Subthemes, and Examples of Issues Discussed by Participants

<i>Themes</i>	<i>Subthemes</i>	<i>Example of Issues Discussed by Participants</i>
Benefits of employment and reasons for being employed	Need for productive activity	Need to make a contribution/feel purposeful Need to avoid preoccupation with ALS Positive effects of employment on mental and physical health
	Personal identification with employment Positive experiences in the workplace	Consideration of job as part of one's lifestyle Positive experience of a supportive environment Loyalty to coworkers Opportunity to be with friends
	Practical benefits of employment	Financial benefits Access to insurance coverage
Negative impact of employment	Impact on physical health	Decline in medical condition Fatigue
	Impact on mental health	Difficulty adjusting to decreased job responsibilities Negative reactions from coworkers
Barriers to employment	Physical/environmental barriers Technological barriers	Lack of accommodations for wheelchairs Cost of assistive technology Learning demands of assistive technology Limitations of assistive technology Lack of appropriate fit with present skills of individual
	Attitude barriers	Negative attitudes toward people with ALS Negative attitudes toward terminal illness generally
	Policy and funding barriers	Lack of enforcement of government policies Absence of employer policies to support retraining Lack of insurance funding for assistive technology
	Financial barriers	Decreased financial compensation resulting from decreased responsibilities Reduction in disability payments when a salary is received
	Information and service barriers	Insufficient number of organizations providing AAC services Lack of knowledge/expertise regarding assistive technology Inequities in services provided to people with ALS
	Barriers related to psychosocial adjustment of people with ALS	Difficulty accepting ALS Difficulty asking for help Physical manifestations/course of ALS
	Government policies	Federal legislation that protects the rights of workers with disabilities
	Information and service delivery supports	Information supports provided by ALS chapters and other organizations Information accessed via the Internet
	Employer supports	Employer policies that support participation (e.g., retraining) Facility accommodations Provision of technology
	Technological supports	Specific device features that support participation (e.g., voice output)
Supports to employment activities	Personal support networks (family, friends, etc.)	Personal care supports Moral support Financial assistance Assistance with transportation

TABLE 4: Summary of Recommendations to Facilitate Employment for Individuals with ALS Who Use AAC

<i>Audience</i>	<i>Recommended Actions</i>
Policy makers	<p>Enforce laws that support the rights of people with disabilities</p> <p>Increase prevalence of long-term care insurance</p> <p>Increase funding of assistive technologies</p> <p>Provide options for leasing of equipment</p> <p>Support equipment exchange programs</p> <p>Guarantee access to medical insurance for all</p> <p>Ensure availability of personal care service</p> <p>Ensure availability of transportation services</p>
Employers	<p>Learn about ALS</p> <p>Facilitate changes in job responsibilities</p> <p>Provide training for new jobs that are more appropriate</p> <p>Support appropriate benefits for employees</p>
Service providers	<p>Provide ongoing technical support</p> <p>Provide ongoing services as needs and skills change</p> <p>Introduce AAC options early, before decline of natural speech</p> <p>Provide computer training for Internet access and communication</p> <p>Increase training of service providers in ALS and AAC</p>
Technology developers	<p>Decrease learning demands</p> <p>Provide instruction/documentation on the Internet</p> <p>Improve quality of speech output</p> <p>Develop lighter, smaller, more portable systems</p> <p>Design more attractive systems</p> <p>Increase diversity of functions in systems (e.g., cellular phones)</p> <p>Increase battery life</p>
People with ALS	<p>Seek out and share information about ALS; educate employers and coworkers regarding ALS</p> <p>Be knowledgeable; know and understand legislation</p> <p>Recognize that ALS will require changes in job and lifestyle</p> <p>Propose accommodations to facilitate continued employment</p> <p>Advocate for yourself and others with ALS</p> <p>Accept AAC; learn AAC technologies early on</p> <p>Make decisions based on personal preferences and needs</p>

necessity and being employed to obtain insurance coverage. As Frank commented, "I still have bills to pay, so I can't stop working."

### **Negative Impact of Employment Activities**

Despite the positive benefits of employment, several participants also presented some negative effects of being employed. Two subthemes emerged from the

discussion within this theme: the negative impact of employment activities on physical health and the negative impact of employment activities on mental health.

### **Negative Impact on Physical Health**

The first subtheme was the negative impact of employment on physical health. The topic of how to balance the need for stimulation and the benefits of

employment with the physical stress of the workplace was widely discussed by participants. Julia explained, "It is possible for an employer to be overly benevolent and to attempt to retain the ALS employee past the point when it is in the individual's best interest." Although employment and productivity are priorities in many people's lives, Julia emphasized that one's physical health should not be compromised for the sake of employment. She discussed the negative effects of pushing herself physically to prove her competence on the job and stated, "When I was working with ALS, I took no sick days, came in on time, and felt I had to prove that I was fit for work."

### ***Negative Impact on Mental Health***

The second subtheme to emerge was the negative impact of employment on mental health. Two specific issues were frequently discussed within this subtheme: the psychological adjustments caused by decreased job performance and responsibilities and negative reactions from coworkers. Participants discussed the difficult psychological adjustments required as job performance declined and responsibilities were reduced owing to changes in their medical status. Participants described feelings of inadequacy, feelings of not being "needed" by the employer, and decreased confidence in their job performance owing to an inability to fulfill their previous job description. For example, Julia explained that as she continued to work for her company, she was unable to fulfill many of her previous responsibilities. She stated,

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—either with the client or within my company—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.

Frank also discussed several effects of employment and focused on the effects of negative reactions and attitudes that he had encountered on the job. He explained, "There is definitely a 'stigma' attached to receiving a terminal diagnosis. The first thing most people think about is separating the terminally diagnosed from the rest of the workforce, lest he/she would depress them in some way and damage productivity . . ." Frank suggested that dealing with these attitudes in a forthright manner was a successful strategy for him. He explained, "I wish I had a dollar for every time I heard someone say something like 'You don't conduct yourself like someone preoccupied with dying.' To which I reply something like 'I don't need help with dying. I could use your help to live better, though.' They get the message."

### **Barriers to Employment Activities**

Seven subthemes emerged from the theme encompassing barriers to employment: (a) physical barriers, (b) technological barriers, (c) attitude barriers, (d) policy and funding barriers, (e) financial barriers, (f) barriers resulting from the limited availability of information and services, and (g) barriers related to the psychosocial adjustment of people with ALS.

#### ***Physical/Environmental Barriers***

The first subtheme addressed the physical and environmental barriers that were encountered by the participants. For one individual (Doug), these were the only important barriers that he faced. Doug commented, "The only barriers I have confronted have been more of the physical nature—those anyone in a wheelchair encounters everyday."

#### ***Technological Barriers***

Problems with technology were discussed frequently. Specifically, the discussion focused on the cost of technology, learning demands, specific features of AAC devices that impeded interaction, and problems finding a good match between the present needs of the individual and the features of the technology.

The cost of technology was a central concern for many of the participants. For example, Julia noted, "When one speaks of choices in augmentative communication devices, one must also consider that cost is a very important part of the equation. Many people cannot afford a sophisticated, computer-driven device."

With respect to the learning demands of augmentative communication devices, Doug echoed the concerns of many of the participants when he stated, "I'm certainly no technology whiz-bang, and my experience with AAC equipment is limited, [but] it does seem manufacturers and developers could do a lot more to ease the way for the end user." At the time of the study, Doug had been learning to use a new communication system. He shared the following information regarding his experience: "There are some bugs to work out, and though it is clear that it will eventually work for me, it is taking *far* longer than I expected. I'm sure that the manual is great, but I can't handle the pages." Kayla also made reference to the complexity of the technology and the difficulties encountered by her care givers relative to her communication devices. She stated, "My nurses are great, but they are completely confused by my AAC equipment."

The participants also discussed many issues related to the negative features of AAC technologies. Most comments pertained to the limited battery life of electronic devices, the size and weight of the sys-



tems, poor durability and reliability, the limited speed of communication, and the poor quality of the synthesized speech output. The quality of speech synthesis and the reduced speed of communication particularly affected the participants' perception of the quality of their communication effectiveness. Julia commented,

Let's face it, though. None of the available devices are like real speech. No matter how good DECTalk™ is, it is still hard to tell a joke or have emphasis. The voices are not my voice; some sound whiny, some sound arrogant. And, of course, the speed is not like normal speech. So, often a moment passes before one can type a comment. And I find it necessary to edit my comments, and therefore my thoughts are sometimes oversimplified.

Blake also expressed concern with her limited ability to participate quickly and fully. She said, "I become very frustrated not being able to fully express myself, coming in later after the communication has moved on."

The fourth and final issue that was identified within the technological barriers subtheme was the difficulty matching systems to the present skills of the individual and adapting systems to the individual's changing needs as ALS progresses. Participants reported that they often ended up using systems that did not fully meet their needs and then struggled to learn the features of the devices. Doug commented on the complexity of AAC systems, which offered many features not applicable to him because he was able to use direct selection with a keyboard. In describing his experience, he stated, "I just couldn't get into it somehow [using scanning software] and didn't feel the need for what was obviously a much slower process." Several of the participants discussed the problems they encountered as their skills and needs changed and they had to make the transition to new technologies. For example, Kayla required a single switch to access a computer; however, she wrote that learning the software and "trying to find different switches to fit [my] changing needs was an ordeal."

### **Attitude Barriers**

Of most concern to the participants were negative attitudes directed at individuals with ALS in the workplace and attitude barriers pertaining to ALS as a terminal illness generally. Frank wrote,

I have encountered individuals who, by their actions, appeared to be saying, "Okay, I acknowledge the horrific nature of your affliction and you have my heartfelt sympathy, but this is a business, and we should not subject our customers to your infirmity; you've fought a good fight, now go home!" They are not malicious and are usually quite polite. Yet their lack of emotional or any other kind of support sends the clear message that business is for the healthy . . . they are resisting the institutional decision to support such individuals [with ALS] and therefore are impeding our expectation of assisted normal life.

Some of the participants focused on the impact of the progressive nature of ALS on attitudes. Julia asked the following question:

Do you think it is harder for companies to assimilate folks with ALS as when they read up on it they see emphasis on how fast our physical condition changes and how for ALS patients it is often difficult for some to keep up because the changes come so quickly? One of my client companies had a wonderful policy of hiring handicapped workers, and I worked with a woman in a wheelchair. However, her condition was stable; her paralysis was due to an auto accident at age 18. Do you think ALS is treated differently due to fear of "terminal illness" or thoughts that a company might only keep an ALS employee working for a few months?

Kayla discussed the attitude barrier related to terminal illness more generally:

One of my pet peeves is the use of the word "fatal" to describe ALS. You're definitely right about people's attitudes. If we're written off as "as good as dead" as soon as we are diagnosed, then why work, why even try? I heard somewhere that in Japan, half the people with ALS choose to continue living on a vent[ilator], while less than 10% of Americans do. That's attitudes and lack of support. We're expected to die, so we do.

### **Policy and Funding Barriers**

In discussing this subtheme, the participants raised the following issues: government policies and laws, employer policies, and funding of assistive technology. They noted, for example, that PL 101-336, the Americans with Disabilities Act (ADA),<sup>4</sup> is meant to protect the rights of people with disabilities. However, the participants discussed their belief that the government's failure to enforce existing legislation resulted in a lack of protection of the rights of individuals with disabilities. As Kayla stated, "We have the ADA, but it's often avoided and doesn't apply to small employers." Julia also contributed to this discussion: "Penalties for companies that do not comply with the ADA actually vary with the size of the company. So, if a company was not supportive and fired the person, in some instances, the 'punishment' is not terribly severe financially."

Participants also discussed the policies of specific employers, including issues related to job changes within a company and profitability considerations.

<sup>4</sup>The Americans with Disabilities Act (ADA) is federal civil rights legislation that provides legal protection from discrimination to people with disabilities and ensures equal access to employment and certain other services. Additional information is available at [www.usdoj.gov/crt/ada/statute.html](http://www.usdoj.gov/crt/ada/statute.html).

Julia brought up the issue of the costs for a company to retain a person with ALS. She said, "There is a limit to what a company can accommodate without disrupting profitability." She discussed the challenges associated with retraining for new positions; however, she saw value in this approach, writing, "I wish there had been a way to put me in another department so that I could have continued contributing longer."

Barriers to the acquisition of assistive technology, including the lack of financial reimbursement from specific insurance policies, were also discussed. For some individuals, these barriers were substantial. Julia stated, "In my case, my insurance policy specifically excludes paying for an augmentative communication device." Kayla also experienced similar problems with her insurance company. "There has been a total lack of support from my otherwise excellent insurance company. They have refused to pay for any communication equipment." For those with funding, the acquisition process was also a concern, as Julia explained: "Many people who are [covered by insurance] are limited to only one device and may end up with one too sophisticated for their immediate needs."

### ***Financial Barriers***

Some of the participants discussed the financial barriers to continued employment. Julia described her situation in some detail. Once the symptoms of ALS made it difficult for Julia to fulfill her pre-ALS work responsibilities, she chose to accept a lower level of work responsibility (and a lower level of compensation) to continue to be part of the workplace. At the same time, her disability benefit payments were reduced by the amount she earned in wages. Overall, her post-ALS financial compensation was significantly lower than her pre-ALS salary, and, in some ways, she was "working for nothing" as whatever she earned was deducted from her disability payment.

### ***Information Barriers***

This fifth type of barrier to employment resulted from a lack of access to appropriate information and services. The participants discussed a range of problems they confronted, including the lack of ALS clinics available throughout the country, the distance they had to travel to obtain services, and the insufficient knowledge and expertise of many service providers regarding AAC technologies and interventions.

A majority of the participants commented that they had identified and procured their AAC technologies independently or through an ALS support group rather than through speech-language pathology services. Although individuals saw benefits to the solutions they had developed, many expressed frustration with the lack of easy access to information about AAC. Doug described some of his experiences with information barriers in the following way:

Looking back, I guess I would say that nearly everything I have learned [about AAC] I have learned on my own. At the major university teaching hospital where I was diagnosed, nothing was mentioned at all. In fairness, I must follow that up by saying that these good people are 100 miles away and only saw me every 4 months or so. Since my symptoms began in my legs and I remained as articulate as ever, the subject just never came up.

Julia discussed the issue of treatment and information inequalities. She asserted:

I find myself getting upset at the way different PALS [People with ALS] seem to have varying access to information and treatment . . . these differences appear to happen regardless of geography, seem to have some relation to patient assertiveness, intelligence, and financial resources, and that is unfortunate.

Kayla highlighted the significant time and effort required of people with ALS and their families to overcome information barriers: "Our ALS clinic had no AAC devices or counseling when I was first diagnosed . . . My husband and I spent a lot of time and money stumbling around . . . it took me 2 years to adjust to life on the vent[ilator] and find the right equipment to be able to work again."

### ***Barriers Related to the Psychosocial Adjustment of People with ALS***

The sixth and final subtheme related to the enormous psychosocial adjustment required of people with ALS. Discussion focused specifically on personal issues and the struggle of coping with the disease. Participants highlighted the struggle to accept the reality of ALS, to overcome the frustrations associated with the disease, and to be able to actively seek help from others. As Kayla stated, "Most people with ALS are just too devastated to fight for the care, equipment, and support they need . . ." Kayla, Frank, and Blake addressed the challenge of learning to ask for and accept assistance from others. They stressed the importance of becoming comfortable asking for help, particularly with personal care issues, so as to be able to participate in productive activities.

Participants also discussed the ongoing challenges of dealing with the progression of ALS. Blake described her experiences:

My barriers have been few and of my own making. First, it was my eating took up most of my time, and then there was the exercises I was supposed to do. Now I feel my drooling is getting in my way; I sit now with a bath towel draped over my lap and a wastebasket at my side . . . I have tons of paper towels and [tissues] always with me. It's embarrassing. Others seem to have accepted it. I can't.

Julia shared Blake's concerns: "For many of us, the salivation problem is a real nuisance to put it mildly . . . I think it is such a emotional bother to us because it is such a visible sign of something not quite right."

### Supports to Employment Activities

In addition to the barriers to employment, the participants also described the supports and strategies they used to overcome these barriers and ensure successful employment experiences. Four subthemes emerged from the theme describing supports to employment: (a) government policy supports, (b) availability of information and services, (c) employer supports and technological supports, and (d) personal support networks.

#### Government Policy Supports

One frequently discussed issue was how federal legislation, specifically the ADA, is beneficial in assisting individuals with disabilities who are employed by larger companies. Julia, in commenting on the ADA, suggested that larger companies would probably have the best policies developed concerning the hiring of individuals with disabilities as they had the "most to lose" if they were not in compliance and were fined. She also noted, however, that she had "no idea" how to bring charges against a company that she believed to be out of compliance.

#### Availability of Information and Services

Discussion of this subtheme focused specifically on supports and services offered by various organizations, especially ALS Association chapters.<sup>5</sup> These chapters are nonprofit organizations dedicated to providing information and support services to people with ALS and their families and care givers. The ALS chapters provided significant supports for the participants by offering information on assistive technology, trained personnel to demonstrate the use of equipment, and equipment-lending services. Additional services and organizations that were sources of information on assistive technology for the participants were the United Cerebral Palsy Association,<sup>6</sup> Muscular Dystrophy Association,<sup>7</sup> and other communication

clinics that provided technical support and a range of technology available for loan. In addition, some individuals received services from professionals at the Office of Vocational Rehabilitation.<sup>8</sup>

The participants also highlighted the importance of access to the Internet. The Internet provided the participants with a vast amount of information relating to assistive technology and access to support networks comprised of other individuals who also have ALS. Commenting on Internet-based supports, Julia indicated, "I don't know what I would have done without the help of the Internet and the help of people I have never met." The *ALS Digest* was frequently mentioned as a useful source of information.

#### Employer Supports

Those participants who were engaged in employment activities in the workplace described the specific accommodations provided by their employers that enabled them to continue participating in their work environments. These accommodations consisted of making facility modifications, providing communication technology required to perform job duties, providing personal care services, offering flexible schedules, and allowing individuals to work from home by providing them with the necessary supplies and equipment. In addition, several employers and human resource personnel researched ALS, and their education and awareness relative to the disease served as a significant support. Although a number of employers offered these supports and accommodations, participants noted that larger companies may offer higher levels of support to individuals with disabilities owing to a larger financial base.

A number of the companies went above and beyond what was required by federal legislation. Frank described the supports offered by his employer, a large company:

In addition to the restroom and other facilities' modifications needed to accommodate my presence on site, my company has made it possible for me to work from home if I choose. However, the absolutely crazy thing that my company did to assure my continuing to work was to arrange for a full-time home health care aide to assist me at work. That is unheard of.

Smaller organizations also demonstrated the commitment to make changes that facilitated continued employment. Blake discussed her experiences with a smaller company as follows:

<sup>5</sup>Information on the ALS Association is available from 27001 Agoura Road, Suite 150, Calabasas Hills, CA 91301-5104, USA, and at [www.alsa.org](http://www.alsa.org).

<sup>6</sup>Information on the United Cerebral Palsy Association is available from 1660 L Street, NW, Suite 700, Washington, DC 20036, USA, and at [www.ucpa.org](http://www.ucpa.org).

<sup>7</sup>Information on the Muscular Dystrophy Association is available from National Headquarters, 3300 E. Sunrise Drive, Tucson, AZ 85718, USA, and at [www.mdausa.org](http://www.mdausa.org).

<sup>8</sup>Offices of Vocational Rehabilitation provide state-sponsored employment counseling and support services for individuals with disabilities in the United States.

Both [of my jobs] have made accommodations so I can continue to work. [One] job has given me a designated parking spot, a laptop computer so I can work from home when I want, and they are getting me a TTY [teletype] with a printer so I can resume talking on the phone.

The participants also discussed approaches to dealing with physical barriers in the workplace. Some said they were provided with specialized furniture and technologies in the workplace, whereas others were presented with other approaches. For example, in the case of Julia, rather than providing accommodations at her office, her employer offered support for her to create a home office. Although this helped Julia to maintain some connection to the world of work, she reported that she felt a loss of responsibility because she was no longer able to carry out some of her former job responsibilities from home.

### ***Technological Support***

The participants cited a range of technological features offered by their various communication systems that enabled them to be actively involved in employment activities. These included voice output, acceleration techniques such as abbreviation expansion, portability, computer access capabilities, and the capacity to store and retrieve messages. Although specific features of some devices frustrated participants, many spoke of the importance of AAC technology in their lives. As Blake commented in describing her device, "I'd be lost without it."

### ***Personal Support Networks***

All participants noted the importance of personal support networks, which included family, friends, church members, neighbors, support groups, and other individuals with ALS. These networks provided the participants with moral support, financial assistance, personal care, and transportation assistance, which enabled them to cope with the disease and continue working. Many of the participants made comments similar to those offered by Frank, who said, "I could not do it without the support I get from a whole lot of friends and relatives who put me to bed, feed me, toilet, shower and dress me, and drive me and my power wheelchair to work every day."

### ***Recommendations***

Although all participants had achieved successful employment, they had to overcome significant barriers to do so. The participants provided a wide variety of recommendations to facilitate employment for individuals with ALS who use AAC, including recommendations to policy makers, employers, service providers, technology developers, and people with ALS themselves. These recommendations are summarized in Table 4.

### ***Recommendations to Policy Makers***

The participants had a number of recommendations to policy makers, including government and insurance agencies. They included strict enforcement of the ADA, particularly for smaller companies; increased prevalence of long-term care insurance<sup>9</sup>; and changes in government policy to improve support for individuals who have ALS, including increased funding of assistive technology, options for leasing equipment, support for equipment exchange programs to accommodate changing needs, guaranteed access to medical insurance, and increased availability of personal care and transportation services. Frank provided the following comments for policy makers:

My message to policy makers would be that while the diagnosis of ALS points to a terminal outcome, for an indeterminate time, our focus will be on maintaining quality of life with or without adjustment. During that time, policy makers owe you and me support for our expectation of remaining productive as long as possible. This goes to the conventional aspects of ADA, including building access and job retention, as well as to health care decisions involving medications and prescriptions, attendant care, durable medical equipment purchases, and new drug development. The point is that we need additional help to live with the terminal diagnosis, and we ought to be able to rely on the policy makers to provide it!

### ***Recommendations to Employers***

The second subtheme entailed recommendations for employers regarding their policies. These recommendations included becoming educated about ALS, facilitating changes in job responsibilities for people with ALS, and offering cross-training options. Julia offered her position to the discussion:

People who want to work and are able to continue in their positions should be able to without fear of losing insurance or retirement benefits. If an individual had a job that really could no longer be done but was fit to do other work, effort should be made to cross-train that individual.

Kayla added, "Maybe we also need job counseling. And we need to educate our employers as soon as we are diagnosed."

### ***Recommendations to Service Providers***

The third subtheme involved recommendations for assisting individuals with ALS to overcome employ-

<sup>9</sup>Long-term care insurance is private medical insurance, purchased by an individual prior to the onset of illness, that funds services not covered by other private or government medical insurance programs. Additional information is available at [www.longterm-careinsurance.org](http://www.longterm-careinsurance.org).

ment barriers. Suggestions included improved services for technology acquisition and support for ongoing use and the early introduction of communication devices before the decline of natural speech. Participants also spoke strongly of the importance of technology in their lives. As Kayla stated, "I believe strongly that every ALS clinic should make computer training and access part of the living with ALS process." Participants also spoke strongly of the need for additional training on the topics of ALS and AAC for service providers.

### **Recommendations to Technology Developers**

The participants provided numerous suggestions to technology developers for improved communication systems. The recommendations ranged from ways to address everyday frustrations (e.g., "I wish my device had a warning of 5 minutes before the battery shuts down") to hopes and dreams for the devices of the future (e.g., using brain waves to communicate). More specifically, participants spoke of their interest in decreased learning demands, documentation available online with simple instructions/tutorials, improved quality of voice output, lighter and more portable equipment, increased compactness of systems, more visually attractive equipment, and a variety of functions available in one device, including cellular phone options. Julia summarized a large number of recommendations related to the quality of voice output as follows:

I wish that there had been a way, when I first knew I would lose my voice, to record my own voice into a computer and have the computer be able to translate the vowel sounds and pitch patterns I used into DECTalk so that my computer would still be me.

Battery life was also a major concern, with participants interested in both longer battery life and electrical systems that could be integrated easily (e.g., the ability to use the battery on the electric wheelchair as a power source for communication devices).

### **Recommendations to People with ALS**

The participants offered a range of suggestions and advice for other individuals with ALS relative to both improving employment outcomes and making a decision about whether to engage in employment activities. Recommendations included the need to seek out and share information about ALS, to recognize that the progressive nature of ALS may necessitate changes in an individual's lifestyle and communication techniques, and to make decisions based on personal preferences and needs.

Many of the participants discussed the importance of knowing and understanding relevant federal legislation and the usefulness of organizations and information services specifically organized by and for individual

with ALS (e.g., the ALS Association, the *ALS Digest*). Blake discussed how she reviewed relevant legislation to be prepared to advocate for necessary changes: "[After reading ADA], I made up a list of things that would help me handle my job and which were reasonable . . . I was pleasantly surprised when they [the employer] accepted most of what I suggested."

Participants discussed the need to share information and advocate on both an individual and a collective basis. Julia made the following comments on the importance of sharing information:

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.

While recognizing the need to meet with employers on an individual basis to discuss needed job accommodations, participants also spoke of the need for group advocacy. Kayla wrote, "Be as visible as possible, write our newspapers and congress persons . . . don't just accept death."

Participants discussed the need to prepare for the changes that ALS would bring, especially the need to be ready to use communication technology. ALS poses particular challenges, as changes in physical functioning can lead to changes in the access techniques that an individual can use. Kayla, while describing to another participant the challenges she might face in learning to make use of switches to access an AAC device, spoke of the need for patience and flexibility while learning new technologies. She wrote, "Don't be surprised at how slow you are [using switches]; this takes patience, and you pick up speed with practice." Participants also spoke of the benefits of learning how to use a particular type of technology (e.g., single-switch technology) before it was physically necessary to use it.

The participants in this discussion also spoke of the importance of making decisions about employment on an individual basis. Kayla spoke of the need to gather information but to then make a decision for oneself. She wrote, "Don't let anyone put a time limit on your life, none of this 2 to 5 years crap. *No one knows, and it's different for everyone.* . . . Keep your options open, and take it one step at a time. You have to do what feels right for you."

## **DISCUSSION**

Employment played an important role in the lives of the five individuals with ALS who participated in this study. Unlike many persons with ALS, these individuals continued employment after a diagnosis was made and spoke strongly of the benefits of participation in

the workplace. One significant factor that may have contributed to successful employment outcomes was the nature of the participants' employment activities. The participants held professional jobs or worked independently; they were able to fulfill their occupational roles despite the physical manifestations of ALS. The study conducted by Fried-Oken (1993) indicated that successful employment for individuals with ALS who require AAC is dependent on the requirements of their jobs. Specifically, Fried-Oken (1993) found that jobs must be text dependent (i.e., reliant on the production of written output or natural/synthesized speech) for employment outcomes to be successful.

It is of interest to note that all of the individuals in this study held jobs in which they were able to complete many of their job responsibilities by producing text-based messages. In addition, the employers of these individuals demonstrated considerable flexibility in allowing these individuals to change when and where they performed duties (e.g., working from home).

Based on these findings, intervention for people with ALS should include computer literacy and Internet training. This will provide individuals with a means of furthering their employment options and present them with easy access to a range of support networks (e.g., *ALS Digest*, chat rooms, information on the Internet). Adequate technical support is also a critical need for people with ALS. This requires knowledge of the technology and accessing options available and continuous assessments of the individual's functioning as ALS progresses (Beukelman & Yorkston, 1989; Mathy et al., 2000). In addition, it may be necessary for service providers to play an advocacy role for their clients to ensure that they are receiving the necessary supports in their work environment and to ensure compliance with government policies.

### Benefits of Employment

The benefits reported by the participants included common advantages of working (i.e., feeling purposeful, positive effects on mental health, financial/insurance benefits). However, the attainment of these benefits became a significant priority for these individuals owing to the negative effects of ALS and the participants' need for intellectual and social stimulation. These results correspond to the findings by Young and McNicoll (1998), who reported that individuals with ALS often used intellectual and social stimulation as a means of coping with the disease. The present study suggests preliminary evidence that for some people, their ability to cope with ALS may improve with the contact and stimulation of a supportive work environment.

### Negative Impact of Being Employed

The negative impacts of employment, as reported by the participants, included the negative effects on one's

physical and mental health, which resulted from either the excessive demands necessary to fulfill job requirements, the work environment itself, or the individual's own determination to continue working despite negative consequences. It will be important for individuals with ALS and their support network to evaluate the "cost" and the benefits of employment and to carefully monitor the viability of continued employment over time.

### Barriers to Employment

The focus group participants described numerous barriers that affected their ability to engage in employment activities effectively or to their fullest potential. These barriers included architectural barriers, technological barriers, attitude barriers, policy/funding barriers, financial barriers, barriers related to the limited availability of information and services, and barriers related to the psychosocial adjustment of persons with ALS themselves.

Barriers related to information and services may be especially problematic for individuals with ALS. As the severity of dysarthria progresses, an individual's ability to rely on natural speech to communicate significantly decreases. Therefore, the implementation of AAC systems is warranted for most individuals diagnosed with ALS (see Beukelman and Yorkston [1989] for a discussion of assessment and intervention procedures for individuals with ALS).

The implementation of AAC can significantly improve the quality of life for individuals with ALS as AAC facilitates independence and control over one's environment (Carroll-Thomas, 1995; Yorkston, 1989; Zeitlin, Abrams, & Shah, 1995). However, because of limited collaboration among AAC professionals and ALS clinics and organizations, many people diagnosed with ALS are not aware that AAC services are available, and therefore many do not receive intervention for their communicative needs (Blackstone, 1988). The lack of quick, easy access to reliable information about AAC, as described by the participants in this study, is clearly a serious concern.

AAC interventions require not only the identification of an appropriate AAC system but also competence in addressing psychosocial concerns (Carroll-Thomas, 1995). Emotional support and encouragement throughout the intervention process can assist in alleviating helplessness and fear while at the same time helping to establish a level of trust among the members of an intervention team. Providing this emotional support and information are two fundamental responsibilities of health care professionals who work with individuals with ALS (Sebring & Moglia, 1987).

### Supports to Employment

Successful employment outcomes were dependent on effective service delivery and technical support.

The supports described by the participants that enabled them to continue working included governmental policies; information and services provided by ALS chapters, other service organizations, and the Internet<sup>10</sup>; supports provided by employers; technological supports; and, finally, supports provided by the participants' personal support networks (e.g., family, friends, neighbors) who assisted with financial, transportation, and personal care needs.

Service providers have a responsibility to offer individuals with ALS a range of information and options so that they are able to make informed decisions and act as causal agents in the intervention process. Participating in decision making can rebuild an individual's sense of self-determination, thereby facilitating improved participation patterns and overall quality of life (Light & Gulens, 2000). The participants in this study spoke frequently of the need for individuals with ALS to make informed decisions about employment, assistive technology, and many other issues. Consequently, service providers should be committed to informing individuals with ALS about employment options. This information will increase awareness that a productive and meaningful future is still possible after a diagnosis of ALS. This point was made clearly by Julia, who said, "We with ALS have a chance to really savor each day. ALS cannot define one's life, or one will have no life. I would tell anyone newly diagnosed to not rush into any decision, to figure out where he is the happiest, and try to go with the flow."

Individuals with ALS should be supported in sharing information with other individuals with ALS. As Bowe, Faye, and Minch (1980) noted, disabled individuals with several years of disability experiences are frequently better aware of the needs of disabled people and better informed about government benefits than are able-bodied professionals in the rehabilitation delivery system. Local ALS chapters often have organized advocacy groups, and the *ALS Digest* is available to anyone with access to the Internet.

### **Recommendations to Overcome Barriers to Employment**

The recommendations for overcoming barriers to employment proposed by the participants included suggestions to those groups that significantly impacted the ability of individuals with ALS to continue to engage in employment activities. It was recommended that technology developers improve the general features of communication systems to facilitate the use and affordability of devices. The participants also provided suggestions to policy makers (i.e., government, insurance, employment) and service providers about the

need for greater awareness of ALS issues to maintain adequate support services. Lastly, the participants offered advice for other individuals diagnosed with ALS. Their words of encouragement emphasized the need for seeking out and sharing information, accepting AAC to enhance communication, and individual decision making. Implicit in many of their comments was the importance of a positive and self-determined attitude; Blake summarized her advice to persons with ALS in three words: "Don't give up."

### **Limitations of the Study**

The results of this study make a significant contribution to the field by advancing our knowledge and understanding of strategies to facilitate employment activities for individuals with ALS. However, the study does have several limitations that should be considered when interpreting the results. First, because of the small number of participants, the findings may not be generalizable to the larger population of employed individuals with ALS who use AAC. To participate, participants required access to a personal computer and knowledge of how to use the Internet; individuals with ALS who had neither but who may have been experiencing successful employment outcomes were not investigated in this study. Therefore, successful employment outcomes for individuals who did not have access to computer technology were not investigated in this study. Finally, it is important to note that this study describes only the experiences of individuals who maintained their jobs and who viewed their experiences as positive. Because of our interest in the supports necessary for "successful" employment experiences, we did not, in this project, seek out individuals who regarded their employment experiences as unsuccessful. Additional research is needed to investigate the negative employment experiences of individuals with ALS or those who do not continue their employment.

### **Directions for Future Research**

Owing to the exploratory nature of this study and the paucity of research related to employment outcomes for persons with ALS who use AAC, there are numerous areas for future research, which will be important to capturing the breadth of successful employment experiences. There is also a need to examine the experiences of persons with ALS who are not successfully employed and who wished to continue employment. In addition, studies examining the experiences and perceptions of others involved in the lives of individuals with ALS (e.g., care givers, families, friends, and employers) relative to employment issues and technological knowledge would provide increased awareness relative to the barriers to employment. Finally, investigations of interventions are warranted to examine the effects of emotional and

<sup>10</sup>Communication Independence for the Neurologically Impaired (CINI) provides current information on AAC interventions for individuals with ALS at [www.cini.org](http://www.cini.org), and can be contacted at Suite 1304, 116 John Street, New York, NY 10038, USA.

informational supports relative to improving self-determination and employment outcomes for individuals with ALS.

The results of this study suggest that the individuals involved in the focus group discussion perceived their participation in employment activities as having a significant priority in their lives. Access to AAC and a positive and self-determined attitude had a significant impact on both their ability to participate in society and the quality of their lives.

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### REFERENCES

- Beresford, S. (1995). *Motor neuron disease (amyotrophic lateral sclerosis)*. London: Chapman & Hall.
- Beukelman, D. R., & Yorkston, K. M. (1989). Augmentative and alternative communication application for persons with severe acquired communication disorders: An introduction. *Augmentative and Alternative Communication*, 5, 42–48.
- Blackstone, S. (1988, July). Maintaining communication for individuals with ALS. *Augmentative Communication News*, 1(3), 1–2.
- Blackstone, S. (1993). Employment in the AAC community: A problem for some . . . but not for everyone. In R. V. Conti & C. Jenkins-Odoriso (Eds.), *Proceedings of the Pittsburgh Employment Conference for Augmented Communicators* (pp. 3–6). Pittsburgh, PA: SHOUT Press.
- Bowe, F., Faye, F., & Minch, J. (1980). Consumer involvement in rehabilitation. In E. L. Pan, S. S. Newman, T. F. Backer, & C. L. Vash (Eds.), *Annual Review of Rehabilitation* (pp. 279–303). New York: Springer.
- Carroll-Thomas, S. (1995). Communication changes and challenges in ALS/MND. *Journal of Speech-Language Pathology & Audiology*, 19, 281–282.
- Fried-Oken, M. (1993). Do AAC users with degenerative neurological disease remain or return to the work force? In R. V. Conti & C. Jenkins-Odoriso (Eds.), *The First Annual Pittsburgh Employment Conference for Augmented Communicators* (pp. 73–78). Pittsburgh, PA: SHOUT Press.
- Light, J., & Gulsens, M. (2000). Rebuilding communicative competence and self-determination with adults who have acquired neurogenic and neuromuscular disabilities. In D. Beukelman, K. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with neurogenic and neuromuscular disabilities* (pp. 137–179). Baltimore: Paul H. Brookes.
- Mathy, P., Yorkston, K. M., & Guttman, M. L. (2000). AAC for individuals with amyotrophic lateral sclerosis. In D. Beukelman, K. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with neurogenic and neuromuscular disabilities* (pp. 183–231). Baltimore: Paul H. Brookes.
- McCarthy, H. (1986). Making it in able-bodied America: Career development in young adults with physical disabilities. *Journal of Applied Rehabilitation Counseling*, 17, 30–38.
- Payne, M. S. (1989). Preparing for group interviews. In T. J. Hayes & C. B. Tatham (Eds.), *Focus group interviews: A reader* (2nd ed., pp. 49–51). Chicago: American Marketing Association.
- Sebring, D. L., & Moglia, P. (1987). Amyotrophic lateral sclerosis: Psychosocial interventions for patients and their families. *Health & Social Work*, 12, 113–120.
- Vaughn, S., Schumm, J. S., & Sinagub, J. (1996). *Focus group interviews in education and psychology*. Thousand Oaks, CA: Sage.
- Yin, R. K. (1994). *Case study research: Design and methods* (2nd ed.). Thousand Oaks, CA: Sage.
- Yorkston, K. M. (1989). Early intervention in amyotrophic lateral sclerosis: A case presentation. *Augmentative and Alternative Communication*, 5, 67–70.
- Young, J. M., & McNicoll, P. (1998). Against all odds: Positive life experiences of people with advanced amyotrophic lateral sclerosis. *Health & Social Work*, 23, 35–43.
- Zeitlin, D. J., Abrams, G. M., & Shah, B. K. (1995). Use of augmentative/alternative communication in patients with amyotrophic lateral sclerosis. *Journal of Neurologic Rehabilitation*, 9, 217–220.

### APPENDIX A: Questions Posted to the Discussion by the Principal Investigator

Topic	Question
Welcome	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 family trip 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!).
Benefits	Perhaps we can start our discussion by talking about the benefits of employment activities. Clearly, maintaining work activities involves considerable effort and persistence, and not everyone makes the same decision. If someone were to ask why you chose to continue working after the onset of ALS, what would you say?

*Appendix A continues on next page.*



APPENDIX A: Questions Posted to the Discussion by the Principal Investigator (*Continued*)

Communication and communication technology	A number of you have mentioned the importance of communication in your lives. What were your experiences in being introduced to assistive technology for communication? Were you provided with choices, and how satisfied were you with the choices provided?
Supports to employment	A number of supports have been mentioned so far: the support of family members, the use of assistive technology, the interest of employers and coworkers. What have been your experiences? What are some of the other supports that have been important in your involvement in employment experiences?
Barriers to employment	We have discussed some of the factors that support participation. I would like to talk a little about the barriers to participation. Some of the topics mentioned/implied so far include negative attitudes, misinformation, lack of access to technology and to technology training. What have been the barriers to participation that you have experienced?
Message to policy makers	It has been very interesting to me that despite the diversity of vocations represented here, many of you have experienced similar experiences with your employers. For the most part, you have described employers that have worked to support your continued employment and/or to ease the transition out of the workplace. On the other hand, insurance companies have received criticism for their failure to provide appropriate funding for technology. My question now is this: What can the government do to assist you in living your life the way you want to, especially as it relates to employment? If you could "run Washington for a day," what are the changes you would make?
Message to communication technology developers	As you have discussed augmentative communication technologies, you have referred to features that you like in augmentative communication technologies (e.g., devices should be light, portable, FREE), and features that you do not like (voices that are "whiny/arrogant" sounding, slow speed of communication). 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 the next generation of technology should include. We would all be sincerely interested in your ideas on this topic.
Message to persons with ALS	What would you say to another individual who learns that he/she has ALS and who is trying to make a decision about employment? In recent days, Julia has raised the important issue of the stress of the physical demands of the workplace. Many of you have spoken of the importance of work and its role in helping to define "who you are." If an individual decides to maintain employment, how do they best communicate information about ALS to an employer without provoking the fixation on the diagnosis that some of you have described. Based on your own experience, and maybe a little on what has been discussed at the Web site, what would you say to someone who works and learns that they have ALS?

APPENDIX B

Operational Definitions of Coding Themes

1. *Benefits of Employment and Reasons for Being Employed*: "something that promotes or enhances well-being; an advantage" (*The American Heritage College Dictionary*). 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 avoiding the negative effects of unemployment.
2. *Negative Impact of Employment*: negative experiences (including social, financial, familial, personal, psychological, or physical) resulting from engagement in employment activities.
3. *Barriers to Employment Activities*: any person, organization, situation, action, or device that impedes an individual's ability to participate in employment activities adequately or to the individual's fullest potential. Barriers can include policies, practices, attitudes, knowledge, skill, information dissemination, access, or physical/medical conditions.
4. *Supports to Employment Activities*: any person, organization, situation, action, or device that enables or assists an individual to participate in employment activities.
5. *Recommendations*: suggestions regarding ways of overcoming barriers to employment based on the participants' personal experiences and ideas. Includes recommendations to persons with ALS and their families, employers, coworkers, policy makers, service providers, medical community, and technology developers.
6. *Description of Employment*: comment that provides information about employment activity but does not include benefits/reasons, negative impacts, barriers, or supports related to employment (e.g., "My duties included . . .").
7. *ALS Issues*: comment or question specific to issues related to ALS and not directly related to employment.
8. *Unrelated Statement*: comment or question that is unrelated to employment or ALS issues, including personal statements (e.g., "I have 33 grandchildren").