# ASSISTIVE TECHNOLOGY LAW CENTER

Suite 507
202 East State Street
Ithaca, New York 14850
(607) 277-7286
Fax: 607-277-5239
E-mail: lgolinker@aol.com

Lewis Golinker, Esq.
Director

## MEMORANDUM

TO: Madeline Ulrich, M.D.

FROM: Lewis Golinker

RE: Supplemental Responses to HCFA Web-Site Comments

Date: September 8, 2000

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I write on behalf of the organizations that submitted the *Formal Request for National Coverage Decision for Augmentative and Alternative Communication Devices*, CAG-00055: the American Speech-Language-Hearing Association, Amyotrophic Lateral Sclerosis Association, Brain Injury Association, Center for Disability and Health, Communication Aid Manufacturers Association, Communication Independence for the Neurologically Impaired, International Society for Augmentative and Alternative Communication, National Association of Protection & Advocacy Systems, National Multiple Sclerosis Society, RESNA, Sunrise Medical, United Cerebral Palsy, and the United States Society for Augmentative and Alternative Communication.

Attached to this memorandum our supplemental responses to the HCFA web-site posting on April 26, 2000 regarding the AAC device *Formal Request*. This memorandum follows the filing of information by Marcia Nusgart, on September 1, 2000. Please view these two documents as the complete submission of our supplemental responses.

In addition to these responses, we again direct your attention to the initial responses to the web-site posting which were submitted to you on June 29, 2000. These responses were discussed with you and Dr. Kang at our meeting on July 6, 2000.

These responses also will supplement the information presented and discussed during your visit to the International Society for Augmentative and Alternative Communication (ISAAC) at its bi-ennial conference, on August 4.

Please call me or send me an e-mail message if you have questions about these supplemental responses.

Thank you.

cc: Jeff Kang, M.D.
Nancy-Ann Min DeParle
Sean Tunis, M.D.
Bob Williams
Henry Claypool

## SUPPLEMENTAL RESPONSES TO HCFA WEB-SITE COMMENTS

### Introduction

The information presented below supplements the following:

- the *Formal Request for National Coverage Decision for Augmentative and Alternative Communication Devices*, CAG-00055, submitted on December 30, 1999;

- the additional written and other information submitted throughout the initial review period, including letters supporting the *Formal Request* from the American Medical Association, American Academy of Neurology and American Academy of Physical Medicine and Rehabilitation; and the in-service educational presentation delivered to you and other HCFA staff on February 24, 2000;

- the initial responses to the HCFA web-site comments submitted on June 29, 2000;

- the discussion at the meeting with Jeff Kang, M.D., and HCFA staff on July 6, 2000, and the information presented during your visit to the International Society for Augmentative & Alternative Communication (ISAAC) bi-ennial conference, on August 4, 2000; and

- the letter and attachments regarding AAC device outcomes submitted to you by Marcia Nusgart on September 1, 2000.

This supplemental response provides an analysis of a sampling of the published and un-published outcomes studies related to a) the ability of individuals with communication disabilities to learn to use AAC devices; and b) the purposes for which AAC devices are used, or stated another way, the benefits derived by these individuals from AAC device use. This analysis samples for discussion large group studies of heterogeneous populations, small group studies and individual case studies and reports.

These studies support the adoption of the proposed Medicare AAC device coverage criteria, as revised, and as submitted to you with the initial responses to the HCFA web-site comments, on June 29, 2000. They demonstrate that:

- individuals with a wide range of neurological/physical condition diagnoses have been evaluated and recommended for AAC devices, have acquired those devices and use them;

- that individuals with all four of the communication impairment diagnoses that are included in the proposed coverage criteria (dysarthria, apraxia, aphasia and aphonia), use AAC devices;

- that AAC devices provide these individuals with the opportunity to meet a wide range of communication tasks, which as a whole comprise the communication needs that arise in the course of their daily activities; and

- that AAC device users are satisfied with the capabilities of these devices and of their ability to use these devices to meet their communication needs, and therefore do not readily seek to change them or stop using them.

In our June 29, 2000 submission to you and in our July 6, 2000 discussion with Dr. Kang, we reported that one topic raised in the HCFA web-site comments could not yet be addressed: a review of the professional literature and other information demonstrating AAC device effectiveness or outcomes. We stated that this review was not yet complete, and that we were in the process of gathering additional information responsive to this topic. We have now completed this effort, and report our findings on the pages that follow.

## HCFA Web-Site Comments, Response to Item 1

In Item 1 of the June 29, 2000 memorandum to you, titled "Identification of Patients, Evaluation Criteria, Outcomes Studies," we reported the text of the HCFA web-site comment:

> The material submitted in support of the request to cover AAC devices is suggestive of the utility of these devices for those with speech impairments, but did not offer sufficient medical evidence to permit identification of those patients; outcomes data supporting the beneficial long term effects of those devices; and criteria for evaluation of patients that would assure that they possess both the physical and cognitive ability to use an AAC device.

We responded to all of the topics raised in this paragraph, except with regard to outcome studies. On that point we stated "[w]e will be providing additional information on this topic in the coming weeks." That information is presented below.

## Supplemental Response

Outcome studies, particularly studies of large groups of individuals, represent a small part of the professional literature about AAC interventions. A number of reasons can be suggested for this fact: first, there is an exceedingly low incidence of AAC device need, *see* Appendix I, Tab E to the *Formal Request*; second, the population of individuals who require AAC devices is exceedingly heterogeneous, (Light, 1999); third, is the truism that the outcomes of provision of an

AAC device are obvious: *with access to an AAC device, the person can communicate, without one, s/he cannot.*

Outcomes can be described as "the result of an intervention," (Frattali, 1998), and "reflect changes in the communication impairment, functional limitation and disability." (Beukelman, Yorkston & Reichle, 2000; Frattali, 1998) It is this definition of "outcome" that is used throughout this supplemental response.

When an AAC device is provided, there will be an immediate and obvious change in circumstance: the individual, who previously could not meet his or her daily communication needs using natural communication methods, will now have a tool available to help accomplish those goals. Stated most simply, the individual will be able to communicate orally, with understandable speech, where before receiving the AAC device this was not possible. Moreover, this change in circumstance is both quantitative and well as qualitative. The following anecdotes by and about adult Medicare beneficiaries who obtained Medicare reimbursement for AAC devices illustrate this point clearly:

> Her communication is enhanced to such a degree with her LightWriter that she can with relative ease and with increased efficiency, converse with anyone she wishes. She can engage friends, relatives, strangers, associates and officials in concise, understandable conversation. She can ask questions, get directions or tell me over the telephone what is going on in her life while inquiring how my family is doing. She is able to communicate verbally as she would be able to . . . , as she has not been able to before the acquisition of the LightWriter tool. In short, she is freed from her non-verbal imprisonment.[1]

> The computer has opened up my life again by allowing me to express my thoughts coherently to myself and others. . . . Although the typing process is slow and laborious for me, the joy of expression and communication is unsurpassed. . . .[2]

> The evidence clearly demonstrates that the claimant, now age 70, suffered a severe stroke rendering the right side of his body non-functional and significantly damaged the communication/transmission part of his brain to the extent that he is mute. His introduction to the computer and subsequent learning of the device has

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[1] Letter dated June 23, 1999 to Medicare Hearing Officer from Dennis Damon, submitted as Exhibit 1 in *In re: Kimberly Damon*, Dkt. No. 000-19-3751 (Social Security Admin. Office of Hearings & Appeals Decision Dated July 28, 2000)(approving LightWriter for adult Medicare beneficiary).

[2] Comment by Medicare beneficiary quoted in *In re: Emyln Jones*, Dkt. No. 360-09-1983, Slip Op. At 3 ((Social Security Admin. Office of Hearings & Appeals Decision Dated Aug. 18, 1993)(approving computer based AAC device for adult Medicare beneficiary).

resurrected to a great measure his ability to communicate and become much more functional to the extent he can maintain greater independent living. . . . There is no question, . . . , that the computer has restored and improved his life. . . . Without this device, . . . , the claimant's life would continue to be severely restricted and his ability to enjoy the fruits of life would not be available.[3]

The record reflects that the beneficiary [who had a stroke] has a history of mental impairments that includes depression and anxiety and which has been largely related to her speech problems. . . . One treatment note reveals that the beneficiary has experienced severe crying episodes from the frustration of not being able to communicate with staff at her facility. . . . However, once the beneficiary began using the ACD [AAC device], the claimant's frustration factor was noted to be reduced 100 % and this reduction was credited to the use of the ACD. Besides benefitting the beneficiary psychologically, treatment notes reveal that the use of the ACD allows the beneficiary to more effectively communicate her medical needs, feelings and desires to her health care providers, the staff in her facility, other residents in her facility and to her family. . . . As a result, treatment notes reveal that she is better adjusted to her therapy plan and goals.[4]

Mrs. Cooper is virtually unable to verbally communicate medical information to her physicians without this [AAC device]. As I stated in the original justification, this places her at great physical risk. . . . ALS is a terrible disease. The inability to communicate, with intact mental and cognitive functions, is perhaps the most devastating aspect of the disease.

* * * * *

For Mrs. Cooper, this equipment [a LightWriter] is the only method that will allow for functional communication. Without it, she cannot even express her medical needs. Unfortunately, she has already been struggling in this situation for many months.[5]

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[3] *Id.*, Slip Op. at page 5.

[4] *In re: Bernadine A.*, Dkt. No. 000-86-0336 Slip Op. at 2 (Social Security Admin. Office of Hearings & Appeals April 27, 1999)(approving Delta Talker for adult Medicare beneficiary).

[5] Letter dated Aug. 7, 1997 to Mr. Javier Perez, HIP Health Plan of Florida, from Jeri Weinstein, M.S., CCC-SLP, submitted as Hearing Exhibit 4; Letter dated Jan. 27, 1998, to Judith Feldt, Center for Health Dispute Resolution, from Jeri Weinstein, M.S., CCC-SLP, submitted as Hearing Exhibit 9; in *In re: Celia Cooper*, Dkt. No. 196-14-0195 (Social Security Admin. Office of Hearings & Appeals Dec. Dated Dec. 2, 1998)(approving LightWriter for adult Medicare beneficiary).

It is equally true that for many individuals there have been no outcomes, because they have not been able to acquire an AAC device. The risk of this adverse consequence has been particularly severe for adults with severe communication disabilities, because of barriers in third party funding programs that have excluded AAC device coverage. For example, in the responses from 46 SLPs throughout the country submitted to you on September 1, by Marcia Nusgart, almost 40 % of the individuals for whom an AAC device was recommended by the SLP were not acquired. Many of the letters submitted to HCFA by physicians during the initial review period also identify funding barriers as a significant issue affecting the potential for AAC devices to produce positive outcomes for their patients.

With the submission of these supplemental responses, it is hoped that the process of eliminating the Medicare barriers to AAC device coverage will be completed, by adoption of the proposed AAC device coverage criteria, submitted to you on June 29, 2000.

*There is a Uniform Goal of All AAC Interventions*

Before addressing the outcome studies that discuss the ability to use AAC devices and the benefits they convey, it is important to re-state that a common clinical goal underlies all AAC device recommendations. Rich Creech, an adult who uses an AAC device, described this goal as enabling the AAC device user to have "effective, independent communication." He explained this goal by stating that *effective communication* is achieved when the AAC device user is able to get his or her message across in a timely, appropriate and relaxed manner. *Independent communication* is achieved when the AAC device user is able to interact with a wide range of people. (Creech, 1995).

AAC clinicians and researchers use the phrase "communicative competence" to describe the goal stated by Creech. Janice Light described this phrase as "the quality or state of being functionally adequate in daily communication and of having sufficient knowledge, judgment and skills to communicate effectively." (Light & Gulens, 2000, Light, 1989, 1997). Communicative competence is described more simply in the professional literature, in the *Formal Request*, and in numerous state Medicaid program AAC device coverage policies as providing an opportunity for an individual to meet the communication needs that arise in the course of daily activities.

AAC devices have the potential to allow individuals to become communicatively competent and to meet those diverse communication needs, as the outcome studies described below will make clear.

## Review of Outcome Studies

The remainder of this supplemental response reviews a sampling of the outcome studies that exist regarding AAC devices. To aid your review, a listing of the contents is provided:

Prior to starting the review of the AAC device outcome studies, an additional body of research should be acknowledged. These studies establish that even before AAC devices are delivered and any outcomes -- positive, neutral, or negative -- are possible, it is common for both the AAC device user and his or her primary communication partners, such as spouse and other family members, to both endorse the recommendation and prescription and to develop strong expectations of *anticipated* benefits in terms of improved communication abilities. (Angelo, 2000). The existence of these expectations creates the potential for AAC devices to fall short in their delivery of benefits. But, as will be explained in the following pages, the provision of AAC devices has been demonstrated repeatedly, in many studies, to meet those expectations and to deliver positive outcomes related to improved communicative competence.

*Studies of AAC Device Use Establish AAC Devices Produce Positive Outcomes*

Research studies, both published and unpublished, confirm that AAC device use produces positive outcomes. These studies, of large and small groups and individual case studies, address: a) the ability of individuals with a variety of communication impairments to use AAC devices; and b) the range of benefits conveyed. Stated below is a sampling of the studies and data that exist, so that HCFA staff can be assured that issuance of the proposed AAC device national coverage decision is supported by outcomes data.

*Studies and Case Reports of AAC Device Use*

*Large, Heterogeneous Group Studies*

Numerous studies confirm that individuals with different neurological conditions are able to learn to use AAC devices. On September 1, 2000, Marcia Nusgart reported to you the results of a survey of the AAC intervention experience of 46 speech-language pathologists. In total, they reported conducting evaluations of 8,646 adults, of whom 3,900 were recommended for AAC devices. The adults who were evaluated and recommended for AAC devices were identified as having more than a dozen different neurological/physical condition diagnoses. The most prevalent conditions listed were ALS, cerebral palsy, stroke, traumatic brain injury, multiple sclerosis and Parkinson's Disease.

These data are consistent with the information presented in the *Formal Request*, which discussed the professional literature related to AAC device need and use by individuals with these conditions. They also reinforce the recommendation by Dr. Michael Weinrich regarding how physical condition diagnosis should be addressed in the Medicare AAC device coverage criteria. Dr. Weinrich stated during the meeting with Dr. Kang on July 6, 2000, that the coverage criteria should include a non-exclusive list of neurological conditions that are associated with AAC intervention and AAC device use. As we reported in the initial responses to the HCFA Web-Site comments on June 29, 2000, that suggestion was incorporated into the revised, proposed AAC device coverage criteria as Coverage Criterion # 1.

Other large group studies confirm the appropriateness of that approach, *i.e.* they support the conclusion that individuals who use AAC devices have a wide range of neurological or physical condition diagnoses. Slesaransky-Poe (unpub. 1997) reported on AAC device use by 45 adults, whose conditions included cerebral palsy, traumatic brain injury and stroke. In July 2000, this study was replicated on a much larger scale: data was collected from 204 respondents, approximately 5 times the original number of participants. The neurological/physical conditions represented among this study population of AAC device users included ALS, cerebral palsy, mental retardation/cognitive disabilities, traumatic brain injury, stroke, and a range of others. (Slesaransky-Poe, unpub. 2000)

Brown-Herman (unpub. 1999) conducted a follow up investigation of 99 individuals for whom an AAC device had been funded by New Hampshire Medicaid between January 1997 and July 1999. Catherine Brown-Herman, the study author is a SLP who designed the NH Medicaid AAC device coverage criteria, and serves as its reviewer for AAC device funding requests. Of this study population, 22 individuals were adults. Their neurological/physical condition diagnoses included ALS, cerebral palsy, aphasia, multiple sclerosis, traumatic brain injury, and mental retardation and other cognitive-developmental disabilities.

Bryen, Slesaransky & Baker (1995) reported on 17 AAC device users who participated in an intensive AAC device training program called ACES (Augmentative Communication and Empowerment Supports). These individuals had neurological/physical condition diagnoses of cerebral palsy and traumatic brain injury.

Murphy, Markova, Moodie, Scott & Boa (1995) reported on AAC device use by 26 AAC device users in Scotland. These individuals had neurological/physical condition diagnoses of cerebral palsy, multiple sclerosis, traumatic brain injury and other mental disabilities.

In 1994, Jinks and Sinteff reported on a follow up study of 76 individuals who had been evaluated and recommended for AAC devices between 1984 and 1990 by a rehabilitation technology team in Pittsburgh. The neurological/physical condition diagnoses reported by the respondents included cerebral palsy, traumatic brain injury, stroke, multiple sclerosis and other neuromuscular disabilities, and other disabilities, including mental retardation and spina bifida.

In Allaire, Gressard, Blackman & Hostler (1991) reported on a group of 110 children with severe communication impairments, 21 of whom used AAC devices. They reported that these devices were used at home, school, with friends and with unfamiliar communication partners.

All of these studies were of individuals who use AAC devices.

*Homogeneous Group Studies and Individual Case Reports*

The large group studies of heterogeneous populations whose individual members use AAC devices are supplemented by many small group studies and individual case reports. The three neurological/physical conditions that are most prevalent in these studies of AAC device use are ALS, cerebral palsy and traumatic brain injury. Illustrations of these studies are discussed below.

*Outcome Studies Related to Individuals with ALS*

That individuals with ALS are able to use AAC devices is well supported by the published literature. (Yorkston, Strand, Miller, Hillel & Smith, 1993; Mathy & Brune, 1993; Mathy, Yorkston & Gutmann, 2000). AAC device use has long been recognized as part of management of ALS (Adams, 1966; Kazandjian, 1997; Yorkston, Miller & Strand, 1995). These facts are

sufficiently well recognized that assessment and provision of AAC devices are within the professional statement of the standard of care for ALS treatment. (Sufit, 1997).

Mathy and Brune (1993) studied use patterns of 11 individuals with ALS who were unable to speak. They were questioned about their daily use of AAC strategies across typical communicative activities/needs. The activities included: communicating immediate needs, face-to-face communication, communicating needs in detail, communicating detailed information, interacting on the telephone, and written communication. All of the individuals were experienced users of multiple AAC systems, which included no technology (*e.g.*, answering yes/no questions), low-tech strategies (*e.g.* alphabet boards), and multipurpose high-tech devices, which provided speech output and written communication. When asked which of their AAC strategies/devices they used most frequently based on communicative activity, all subjects indicated that they relied primarily on their no-tech and low-tech strategies for quick conversation and to communicate immediate needs. High-tech strategies were used primarily for indicating needs in detail, providing detailed information, for the telephone and for written communication activities.

Mathy (1996) and Mathy, Yorkston and Gutmann (2000) reported on AAC use patterns of 36 individuals with ALS. Of this group, 20 individuals had initial spinal symptoms and 16 had initial bulbar symptoms. None of these individuals had functional speech. All used multiple methods of communication including partner dependent techniques (*e.g.*, gestures, eye-blinks), and low-tech strategies (letter boards), and 33 of the 36 used voice output communication devices.

The 1996 and 2000 studies reported that individuals with ALS used different communication techniques depending on the type of communication and the communication partner. Those with initial spinal symptoms generally chose unassisted or low-technology methods to communicate in conversation and for quick needs or wants. They most often chose high technology methods for the rest of their communicative activities. These individuals and their families emphasized the superiority of high-technology multipurpose devices for communicating detailed needs and wants. In contrast with immediate needs (*e.g.* "wipe my mouth") that can often be communicated with eye gaze (*e.g.*, look at a wash-cloth used for wiping the mouth), or a few words, detailed needs require a few sentences to communicate effectively. Communicating a lengthy message using partner-dependent low technology or unassisted strategies can be extremely taxing and frustrating for the AAC device user and partner. High-technology, multi-purpose devices allow the user to construct detailed messages independently that can be printed or saved to display for communication partners as required.

By contrast, because of the greater upper-extremity function of the bulbar group, all of the individuals reported use of handwriting for quick, basic needs and wants, and the majority of them used handwriting for face-to-face conversation. Half of this group relied on handwriting for all communicative activities except talking on the telephone. However, for more than half of this group, the need to use the telephone was the primary reason they obtained a voice output communication device. Three of these individuals lived alone while the others were home alone

during the day while their spouses worked. In communicative activities requiring greater verbal output -- communicating detailed needs, providing detailed information and telling stories -- half the bulbar group reported that they used their high-technology devices most of the time, and half primary relied on handwriting.

Mathy, Yorkston and Gutmann (2000) also provided preliminary results of a study of another group of six individuals. Their initial findings were that the communication method or technique varied based on both the communication task as well as whether the communication partner was familiar or unfamiliar. In general, these individuals use their unassisted and low-technology methods for communicating in conversation and to indicate quick needs and wants, and their high-technology methods for communicating detailed needs and wants, for written communication and for telling stories. However, when the exchange was with an unfamiliar communication partner, they used their high technology devices for almost exclusively. The authors concluded: "[i]t can be inferred from these findings that if their high-technology methods were not available, these individuals would be less likely and less able to engage in conversations or indicate their needs with unfamiliar partners."

At the August 2000 conference of the International Society for Augmentative and Alternative Communication (ISAAC), Doyle and Yonemori reported on a study they conducted of 22 individuals with ALS. Their findings were similar to those previously reported: the individuals in their study used their unassisted communication strategies and low-technology AAC devices for basic communication of quick needs and wants with their most familiar communication partners, and their high-technology AAC devices for communicative activities requiring greater verbal output such as communicating detailed needs or sharing information. (Molly Doyle was one of the speech-language pathologists who met with you during your visit to the ISAAC Conference on August 4.)

The specific uses of AAC devices reported in these studies of individuals with ALS are consistent with the data reported about approximately 4,000 individuals with heterogeneous neurological/physical conditions reported by Marcia Nusgart on September 1, 2000. The responses to Question 12 of that survey identify the purposes for which AAC devices were recommended and how AAC devices were used.

*Outcome Studies Related to Individuals with Cerebral Palsy*

Numerous studies also have been conducted about AAC device use by individuals with cerebral palsy. Yorkston (1996) in a review article about treatment efficacy for individuals with dysarthria, wrote:

> The majority of published reports related to treatment efficacy in cerebral palsy involve application of assistive technology. In the last decade, the field of augmentative communication has developed tremendously in its ability to enhance the communication of individuals with severe physical disability and dysarthria.

This growth has been aided by important changes in technology that allow such features as intelligible synthetic speech output, portability, and flexible but varied means of access to the devices.

Examples include DeRuyter and Lafontaine (1987), who reported on 66 non-speaking individuals with cerebral palsy, 43 % of whom used electronic AAC systems. Other group studies of individuals with cerebral palsy were conducted by Udwin and Yule (1991a; 1991b), while single- subject studies were conducted by Dattilo and Camarata (1991) and Geis-Zaborowski and Silverman (1986). Individual case reports also have been prepared by Ferrier (1991); Goossens (1989); Odom & Upthegrove (1997); and Spiegel, Benjamin and Siegel (1993).

*Outcome Studies Related to Individuals with Traumatic Brain Injury*

Many other studies have addressed AAC device use by individuals with traumatic brain injury (DeRuyter & Lafontaine, 1987; DeRuyter & Donoghue, 1989; DeRuyter & Kennedy, 1991; Doyle, Kennnedy, Jausalaitis & Phillips, 2000; Dongilli, Hakel & Beukelman, 1992; Culp and Ladtkow, 1992). Sufficient information is known about the communication impairments of this population that detailed assessment protocols have been developed, *e.g.*, Culp and Ladtkow, (1992), which have been incorporated into the proposed coverage criteria as Coverage Criterion # 4.

These studies confirm that individuals who have reached the later stages of recovery/ higher levels of cognitive functioning (*e.g.*, Rancho Scales, Levels VI-VIII) and who remain severely dysarthric or apraxic can use and benefit from permanent AAC solutions. DeRuyter and Kennedy (1991) found a direct relationship between the primary type of AAC system used and the individual's level of recovery of cognitive functioning. As cognition improved, more complex AAC systems were provided and used (Carlisle & Culp, 1988; DeRuyter & Donoghue, 1989; DeRuyter & Kennedy, 1991; Fried-Oken & Doyle, 1992). For example, Light, Beesley & Collier (1988) reported on the changes in communication strategies used by an adolescent with TBI who was followed for a period of 3 years. Initially, the treatment goal for this youth was to establish a yes-or-no response, which later changed to use of an electronic AAC device, and finally changed to re-establishment of natural communication methods. These studies show that as cognitive recovery progresses, the purposes of communication change, *i.e.*, from communication limited to expressions of basic needs and wants to the ability to share information and maintain social closeness (DeRuyter, Becker & Doyle, 1987; DeRuyter & Kennedy, 1991). And, as the scope of communication broadens, the use of electronic voice output communication aids becomes more appropriate.

*Summary*

The preceding paragraphs support, hopefully in an amount sufficient to meet HCFA staff's data requirements, the following three conclusions:

- first, that individuals with a wide range of neurological/physical condition diagnoses are able to use and benefit from AAC devices;

- second, that there is no basis in the professional literature related to AAC device use, whether published or unpublished, that coverage for AAC devices should be limited to an exclusive list of neurological/physical conditions; and

- third, that the most appropriate way in which neurological/physical conditions should be addressed in the Medicare AAC device coverage criteria is by the approach recommended by Dr. Michael Weinrich, which is to include a non-exclusive list of diagnoses such as the one stated in proposed Coverage Criterion # 1.

*Outcome Studies Focusing on Communication Impairment*

Outcome studies of AAC device use also reinforce the conclusion that Medicare coverage of AAC devices should be extended to individuals with dysarthria, apraxia, aphasia and aphonia. As noted in the HCFA Web-Site Comments dated April 26, 2000, the discussion in the *Formal Request* adequately addressed dysarthria and apraxia of speech, but comments/questions were raised regarding the appropriateness of coverage for individuals with aphasia and aphonia.

The initial responses to the HCFA Web-site comments included information relevant to inclusion of coverage for both aphasia and aphonia. As to individuals with aphasia, the outcome data that were submitted were gathered through an informal investigation conducted by David Beukelman. Dr. Beukelman sought evidence from AAC clinicians of individuals with aphasia who demonstrate routine use of AAC devices. "Routine use" was specified as: (1) use of the device in daily life outside of rehabilitation, clinic or research settings, and (2) use of the device for at least 12 months. His investigation yielded the following data:

> Reports were submitted [by clinicians] for 16 individuals with aphasia due to stroke who routinely used high-tech AAC devices. Twelve were males and 4 were females. The mean age was 60 years (Range: 44-79 years). All had expressive, non-fluent aphasia with an accompanying severe apraxia of speech. The severity of aphasia was mild for 3 individuals, moderate for 6 individuals and severe for 7 individuals. Eighty-two (82) percent of these individuals used synthesized speech AAC devices, while the remaining 18 percent used digitized speech AAC devices.[6]

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6 Memorandum dated June 27, 2000 to Lewis Golinker, from David Beukelman, Ph.D., Barkley Professor of Communication Disorders and Director of Research and Education, Munroe/Meyer Institute for Genetics & Rehabilitation, University of Nebraska Medical Center - Lincoln, attached as Exhibit 4 to the initial responses to the HCFA Web-site comments, June 29, 2000.

On July 6, 2000, during the meeting with Dr. Kang, Dr. Weinrich supported Medicare AAC device coverage for individuals with this degree of aphasia.

The initial responses to the HCFA Web-site comments also included information secured from the American Speech-Language-Hearing Association regarding the appropriateness of Medicare AAC device coverage for individuals with aphonia. These data also were submitted to you on June 29, 2000 and discussed at the meeting with Dr. Kang on July 6.

The outcome data reported to you on September 1 by Marcia Nusgart provide an independent foundation for adoption of Medicare AAC device coverage for individuals with all four of these communication disability diagnoses. Each of these communication disabilities was represented among the 3,900 adults who were evaluated by SLPs and recommended for AAC device use. These data support the conclusion that individuals with all of these communication disability diagnoses have the ability to use AAC devices.

***Summary***

The outcome data included in the *Formal Request*, which were supplemented by the information submitted with the initial responses to the HCFA Web-site comments, and which have been further supplemented here, support the proposed Medicare AAC device Coverage Criterion # 3. That Coverage Criterion identifies dysarthria, apraxia, aphasia and aphonia as the communication impairment diagnoses for which further consideration of AAC device need is appropriate.

The data discussed above related to traumatic brain injury and aphasia also provide information relevant to the specific findings related to the severity of these communication disability diagnoses that are included in proposed Medicare AAC device Coverage Criterion # 4.

***Studies of Benefits Conveyed by AAC Device Use***

Both published and unpublished studies of AAC device outcomes describe the wide range of benefits conveyed by AAC device use. Examples of these studies are described on the following pages.

The studies reported below describe more specifically ***how*** AAC devices serve as tools that enable individuals to become more communicatively competent, *i.e.*, meet the communication needs arising in their daily activities. Attention should be directed to the description in these studies of the specific purposes for which AAC devices are being used. Those uses, which represent communicative abilities that cannot otherwise be achieved by these individuals, are the positive outcomes that inure to individuals who use AAC devices.

Some of these benefits already have been mentioned. The discussion, above, describing the outcome studies by Mathy and her colleagues, and as further supported by the survey reported

by Marcia Nusgart, identifies the typical uses of AAC devices. These outcomes or benefits of providing AAC devices include, *inter alia*:

- enabling individuals with severe communication disabilities to engage in conversation with family and friends;

- enabling communication by telephone, an essential factor for individuals who live alone or who are left alone for significant periods of time during the day;

- enabling communication with unfamiliar communication partners;

- enabling communication with more than one person at a time; and

- enabling communication of detailed information about needs and wants.

Other studies describe outcomes more generally, such as improved communication skills, including increased conversational participation by AAC device users (Dattilo & Camarata, 1991), and increased spontaneously initiated requests (Glennen & Calculator, 1995). Brown-Herman's 1999 follow-up study of 99 individuals who were provided AAC devices by NH Medicaid from January 1997 to July 1999 yielded similar data. She reported that as a result of access to AAC devices:

- 83.5 % of the respondents reported improved intelligibility of messages;

- 64.3 % of the respondents reported improved ability to participate in conversation;

- 72.2 % of the respondents reported an increase in the number of communication partners;

- 63.5 % of the respondents reported improvement in the AAC device user's general feeling of well-being, state of mind, and self-image; and

- 64.3 % of the respondents reported that the AAC device was in constant, or at least daily use.

Brown-Herman (unpub. 1999).

Brown-Herman reported that these responses were consistent across a variety of variables, including whether the AAC device user was an adult (22 individuals in study sample) or child (77

individuals in study sample); whether the communication impairment was developmental or acquired,[7] and independent of the type of AAC device provided.[8]

These conclusions are further supported by Angelo (2000), who conducted a study of 114 families of children that had been provided AAC devices between 1985 and 1996 by a state-funded long term assistive device loan program in Pennsylvania. She reported that as a result of access to AAC devices:

- 62.6 % of the AAC device users related better to professionals as a result of using their AAC devices;

- 52.8 % of the AAC device users related better to their peers with the devices than before they were acquired;

- 54.6 % of the parents of AAC device users reported that communication was enhanced, and 52.3 % reported that communication was unrestricted as a result of AAC device use;

- approximately half the parents reported better relationships with their children as a result of an improved ability to communicate, which also extended to a similar percentage reporting improved relationships with extended family members;

- 74.5 % of the parents and 67.0 % of the AAC device users reported that they held a positive attitude toward their AAC devices; .

- 60.8 % of the respondents reported the improved ability to express frustration, as well as positive emotions (63.6 %), negative emotions (58.0 %), emotional well-being (51.4 %) and physical well-being (53.5 %).

- 56.1 % of the respondents reported greater independence of the AAC device user as a result of access to the AAC device.

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7 The largest single neurological impairment among study participants was cerebral palsy (28/99); 10 other developmental impairments were represented. In addition, study participants included individuals with ALS (2); aphasia (1); multiple sclerosis (1) and traumatic brain injury (1).

8 Among the 99 AAC devices that had been funded to study participants, 20 were digitized speech output devices with less than 10 minutes of recording time; 8 were digitized speech output devices with more than 10 minutes of recording time; and 63 were AAC devices with synthesized speech output. The other 8 individuals received AAC device accessories.

Another measure that illustrates the benefits conveyed by AAC devices is the frequency of their use. Brown-Herman, for example, found that 64.3 % of the respondents (74/115) reported that the AAC device was in constant, or at least daily use. (Brown-Herman, unpubl. 1999). Likewise, Jinks and Sinteff (1994), in their follow-up study of 45 individuals who had acquired AAC devices following SLP evaluation and recommendation in the period between 1984 and 1990, reported that 38 (84 %) used their AAC devices often or sometimes, while only 3 (7 %) reported that they did not use their devices at all.

*1997 Communicative Effectiveness Study*

In 1997, Graciela Slesaransky-Poe, as part of her Ph.D. dissertation requirements, completed a large group study that addressed the communicative effectiveness of individuals who used AAC devices. Sixty five individuals participated in this study, 45 of whom used AAC devices. This study subsequently received two research awards from the American Association on Mental Retardation. (Slesaransky-Poe, unpub. 1997)

Slearansky-Poe sought to determine whether the use of voice-output communication devices ("AAC devices") made a difference in the communicative effectiveness of adults with significant communication disabilities. "Communicative effectiveness" or "communicative competence" describe an individual's ability to meet the communication needs arising in the course of daily activities. (Light & Gulens, 2000; Light, 1989, 1997)

To conduct her research, Slesaransky-Poe developed a survey instrument, the *Consumer Survey on Communicative Effectiveness*, which measured communicative effectiveness in five areas: general communication, independence, productivity, inclusion and satisfaction. The survey compared communicative effectiveness in each of these areas in two ways: first, when individuals use AAC devices and when these individuals attempt the same communicative tasks without their devices; and second, as compared to the communicative effectiveness of individuals who use non-voice output communication aids performing the same tasks.

The findings of this study were that AAC device use significantly improves the communicative effectiveness of individuals with severe communication disabilities across all five of the areas that were examined. AAC device use allows for significantly improved communication for such individuals as compared to communication without the use of the AAC device, or with a non-voice output communication aid:

- adults with significant communication disabilities who use voice output communication devices (AAC devices) communicate more effectively than people with significant communication disabilities who do not use AAC devices; and

- adults with significant communication disabilities who use voice output communication devices (AAC devices) communicate more effectively when they use their AAC devices than when they do not use them.

The 45 AAC device users who participated in this study were adults. Their mean age was 36 years, with a range from age 18 to 67. Approximately two-thirds were male and one-third was female. The participants resided in 15 states. More than 90 % had completed high school, and approximately 30 % had completed at least 2 years of college.

These 45 participants had three primary neurological diagnoses: for 41 it was cerebral palsy (91 %); for 3 it was brain injury (7%); and for 1 it was stroke (2 %).

Seven types of AAC devices were being used, with examples in each of the three AAC device categories proposed for Medicare coverage:

Category I: digitized speech output communication devices:

| | |
|---|---|
| Message Mate | 2.3 % |

Category II: synthesized speech output communication devices that require spelling for message production and physical contact direct selection for access:

| | |
|---|---|
| Light Writer | 2.3 % |

Category III: synthesized speech output communication devices that permit multiple methods of message production and multiple methods of access:

| | |
|---|---|
| Liberator, Touch Talker, Light Talker, Computer with AAC Software, Real Voice | 95.4% |

These devices were accessed as follows:

| | |
|---|---|
| Physical Contact Direct Selection by hands or fingers: | 53.5 % |
| Physical Contact Direct Selection by pointing sticks (head, mouth, chin): | 27.9 % |
| Total, Physical Contact Direct Selection: | 81.4 % |
| Direct Selection with an Electronic Aid: | 4.7 % |
| Indirect Selection (joystick, switches): | 13.9 % |

These 45 individuals were asked to complete the *Consumer Survey on Communicative Effectiveness* twice: for when they used their AAC devices, and when they attempted the same tasks without their devices. A second group of 20 individuals, with similar demographic

characteristics, but who do not use voice-output communication devices, also completed the survey.

The results of this study were clear: the communicative effectiveness of individuals who use AAC devices was significantly greater than individuals with severe communication disabilities who do not have AAC devices, and signficantly greater than when the AAC device users attempt the same tasks without their devices. These results were consistent for all five sections of the *Consumer Survey on Communicative Effectiveness.*

The five sections of the *Consumer Survey on Communicative Effectiveness* were: General Communication, Independence, Productivity, Inclusion and Satisfaction. The General Communication section asked 5 questions about communication activities with familiar and unfamiliar partners, requesting and providing information (asking and answering questions), and speaking to groups of people. The results were as follows:

**Table 5. General Communication Section Scores of the *Consumer Survey on Communicative Effectiveness* for VOCA and Non-VOCA Groups**

| Group | Mean (s.d) | Range |
|---|---|---|
| VOCA | | |
| With device | 21.73 (2.70) | 16 to 25 |
| Without device | 12.13 (3.60) | 6 to 21 |
| Non-VOCA | 15.45 (5.12) | 5 to 25 |

Responses to the General Communication section indicated that when participants of the VOCA group use their voice output communication devices, they communicate significantly more effectively than the participants of the Non-VOCA group [$t(63) = 6.48$, $p < .001$]. Responses also indicated that the communicative effectiveness of the people in the Non-VOCA group was significantly higher than the people in the VOCA Group when they do not use their communication devices [$t(63) = -2.99$, $p = .004$].

The Independence section of the survey asked seven questions about how effectively individuals communicated with personal assistants, physicians and other health care providers, when using public transportation, with food service personnel and when talking over the telephone. The survey also inquired about how independent the individuals were, and how important to them it was to be independent. The results were as follows:

**Table 6.** **Independence Section Scores of the *Consumer Survey on Communicative Effectiveness* for VOCA and Non-VOCA Group**

| Group | Mean (s.d) | Range |
|---|---|---|
| VOCA | | |
| With device | 22.62 (5.38) | 12 to 30 |
| Without device | 12.73 (4.43) | 6 to 27 |
| Non-VOCA | 17.15 (5.16) | 9 to 27 |

As with the total instrument, the Independence section had two scores for the VOCA group, (i.e., when they are using their devices and when they are not) and one score for the Non-VOCA group. As shown in Table 6, out of a possible range from 6 to 30 for this section, the mean score for the VOCA group when using their voice output communication devices was 22.62 (s. d. = 5.38), with values ranging form 12 to 30; and 12.73 (s. d. = 4.43) with values ranging from 6 to 27 when not using their communication devices. The Non-VOCA group, obtained a mean score of 17.15 (s. d. = 5.16) with values ranging from 9 to 27. Significant differences were found in the levels of independence (as they relate to communicative effectiveness): (a) between the VOCA group when using their devices and Non-VOCA groups [ $t(63) = 3.83$, $p < .001$]; (b) between the VOCA group when not using their devices and the Non-VOCA group [ $t(63) = -3.52$, $p = .001$]; and (c) within the VOCA group when using and not using their voice output communication devices [ $t(44) = 10.55$, $p < .001$].

As noted above, the survey also asked about how independent the study participants believed themselves to be. In response, the following results were reported:

> [o]ut of the 45 participants of the VOCA group the majority (84.4%) considered themselves to be either very independent or independent when they used their devices. However, only 17.8% considered themselves to be independent, and almost half of them (44.4%) considered themselves as either not so independent or not independent at all when they do not use their devices. There was a significant difference between participant's perceptions about their independence when they use (possible range 5 to 1, mean = 4.4) and when they do not use (possible range 5 to 1, mean = 2.4) their voice output communication devices [$t(44) = 9.61$, $p < .001$].

The Productivity section of the survey asked 3 questions about how effectively the participants communicate in whatever activity they do during the course of the day, such as work, school, day program, *etc.* In addition, participants were asked how productive they believed they were. The results were as follows:

**Table 9: Productivity Section Scores of the *Consumer Survey on Communicative Effectiveness* for VOCA and Non-VOCA Groups**

| Group | Mean (s.d) | Range |
|---|---|---|
| VOCA | | |
| With device | 8.93 (1.50) | 4 to 10 |
| Without device | 5.11 (2.16) | 2 to 10 |
| Non-VOCA | 7.15 (5.12) | 4 to 10 |

Significant differences were found in the levels of productivity (as they relate to communicative effectiveness): (a) between the VOCA group when using their devices and Non-VOCA group [ $t(63) = 4.00$, $p < .001$]; (b) between the VOCA group when not using their devices and the Non-VOCA group [ $t(63) = -3.81$, $p < .001$]; and (c) within the VOCA group when using and not using their voice output communication devices [ $t(44) = 10.35$, $p < .001$].

In addition, in response to the question asking how productive the participants believed themselves to be, the responses clearly showed that individuals felt significantly more productive when they used their AAC devices than when they did not use them, and as compared to individuals who do not have AAC devices:

> [o]ut of the 45 participants of the VOCA group the majority (90%) considered themselves either very productive or productive when they used their devices. However, when not using their communication devices, only 17.8% considered themselves to be productive, and over half of them (51.24%) considered themselves as either not so productive or not productive at all. There was a significant difference between participant's perceptions about their productivity when they use (possible range 5 to 1, mean = 4.4) and when they do not use (possible range 5 to 1, mean = 2.4) their voice output communication devices [$t(44) = 9.44$, $p < .001$].

The fourth section of the survey addressed "inclusion." This section contained six questions which measured how effectively the participants communicated with people they meet

in their communities, with their friends, or with those they meet in public places such as restaurants and stores, and lastly, how effectively they can tell others how they feel. And, as in the independence and productivity sections, participants were asked to describe how included they felt. The results were reported as follows:

**Table 12. Scores for the VOCA and Non-VOCA Groups in Inclusion Section of the *Consumer Survey on Communicative Effectiveness***

| Group | Mean (s.d) | Range |
|---|---|---|
| VOCA | | |
| With device | 20.82 (4.04) | 10 to 25 |
| Without device | 12.16 (4.58) | 5 to 25 |
| Non-VOCA | 16.30 (4.64) | 6 to 23 |

As shown in Table 12, out of a possible range from 6 to 30 for this section, the inclusion mean score for the VOCA group when using their voice output communication devices was 20.82 (s. d. = 4.04), with values ranging form 10 to 25; and 12.16 (s. d. = 4.58) with values ranging from 5 to 25 when not using their communication devices. The Non-VOCA group obtained an inclusion mean score of 16.30 (s. d. = 4.65) with values ranging from 6 to 23. Significant differences were found in the levels of inclusion (as they relate to communicative effectiveness): (a) between the VOCA group when using their devices and Non-VOCA group [ $t(63) = 3.98$, $p < .001$]; (b) between the VOCA group when not using their devices and the Non-VOCA group [ $t(63) = -3.28$, $p = .002$ ]; and (c) within the VOCA group when using and not using their voice output communication devices [ $t(44) = 10.35$, $p < .001$].

In response to the question about how included study participants believed themselves to be, the following was reported:

> [o]ut of the 45 participants of the VOCA group 67.7% considered themselves to be either very included or included when they used their voice output devices. However, when not using their devices, only 17.8% considered themselves to be included, and over half of them (66.2%) considered themselves as either not so included or not included at all. There was a significant difference between participant's perceptions about their inclusion when they use (possible range 5 to 1, mean = 3.8) and when they do not use (possible range 5 to 1, mean = 2.2) their voice output communication devices [$t(44) = 6.55$, $p < .001$].

The final section of the survey related to "satisfaction." The questions in this section asked about the levels of participants' satisfaction with their overall communicative abilities; with their communication in different areas of their lives, such as at home, at their daily activitiy and when participating in recreational activities. The responses to these questions were reported as follows:

**Table 16. Scores for the VOCA and Non-VOCA Groups in Satisfaction Section of the *Consumer Survey on Communicative Effectiveness***

| Group | Mean (s.d) | Range |
|---|---|---|
| VOCA | | |
| With device | 17.91 (2.98) | 8 to 20 |
| Without device | 10.56 (3.89) | 4 to 19 |
| Non-VOCA | 13.80 (4.47) | 4 to 20 |

As shown in Table 16, out of a possible range from 4 to 20 for this section, the satisfaction mean score for the VOCA group when using their voice output communication devices was 17.91 (s. d. = 2.98), with values ranging form 8 to 20; and 10.56 (s. d. = 3.89) with values ranging from 4 to 19 when not using their communication devices. The Non-VOCA group obtained a satisfaction mean score of 13.80 (s. d. = 4.47) with values ranging from 4 to 20. Significant differences were found in the levels of satisfaction (as they relate to communicative effectiveness): (a) between the VOCA group when using their devices and Non-VOCA group [ $t(63) = 4.38$, $p < .001$]; (b) between the VOCA group when not using their devices and the Non-VOCA group [ $t(63) = -2.96$, $p = .004$]; and (c) within the VOCA group when using and not using their voice output communication devices [ $t(44) = 10.65$, $p < .001$].

By comparing the overall satisfaction with their communication, once again, noticeable differences were found between the people in the VOCA group when they use their communication devices and when they do not use them, as well as with the people in the Non-VOCA group.

Table 17 showed that the majority (86.7%) of the participants in the VOCA group were very satisfied or satisfied with their overall communication when they use their communication device. The percentage diminished to 13.4% when they were not using their communication devices. People who do not use communication devices (mean = 3.1) were more satisfied with their communication than people in

the VOCA group when are not using their communication devices (mean = 2.4) [t (32.20) = -2.10, p = .004], but significantly less satisfied (mean = 3.1) than the people in the VOCA group when they use their communication devices (mean = 4.5) [t (26.44) = 4.34, p <.001].

**Table 17. Overall, How Satisfied With Your Communication Are You?**

| | VOCA Group | | Non-VOCA Group |
|---|---|---|---|
| | When using AAC Device | When not Using AAC Device | |
| | % | % | % |
| Very Satisfied | 68.9 | 6.7 | 15 |
| Satisfied | 17.8 | 6.7 | 20 |
| So-So | 11.1 | 31.1 | 20 |
| Not so Satisfied | 2.2 | 28.9 | 30 |
| Not Satisfied At All | 0 | 26.7 | 15 |

*Summary of Findings*

The data reported by Slesaransky-Poe (unpub. 1997) provide clear evidence that AAC device use significantly improves the communicative effectiveness of a diverse group of people with severe communication disabilities. Based on their increased communicative effectiveness, AAC device users are able to accomplish more, and be more productive and independent. AAC device users also are far more satisfied with their communicative abilities than when they attempt to communicate without their devices and as compared to those who do not have access to AAC devices.

This study is a significant contribution to the outcome literature regarding AAC device use, and as is explained further in the text that follows, the findings in this study have recently been replicated with a much larger study population, and are consistent with the findings of other AAC device use outcome studies. It demonstrates the importance of having additional therapeutic tools available for individuals with communication disabilities who are not able to meet their communication needs through use of natural communication methods and AAC techniques that do not include a voice output communication aid. This is the specific SLP finding that is required by proposed Coverage Criterion # 5. This study makes clear that individuals' communicative effectiveness can be significantly enhanced if they use an AAC device as compared to attempting (or being required) to rely solely on other AAC strategies.

This study also confirms the observations by AAC device users that:

"Speech isn't everything, but communication is."

J. Renuk (1986).

"To speak is a wonderful gift, whether it is through our mouths or with speaking aids."

R. Stankowski (1984).

As noted above, this study supports the the fifth proposed coverage criterion. It also supports the first proposed coverage criterion which states a non-exclusive list of physical condition diagnoses. This study shows that individuals with different underlying physical conditions can benefit from AAC devices. There is no reason, as has been stated repeatedly and by many knowledgeable sources, to consider limiting Medicare AAC device coverage to specific physical condition diagnoses.

This study also complements the data collected in the survey reported by Marcia Nusgart on September 1. In response to question 12 of that survey, the 46 SLPs who provided data identified the purposes for which AAC devices are used. Slesaransky-Poe's study complements those reports by providing the "why" AAC devices are used for those purposes. AAC devices are used for these purposes because they -- as compared to other available communication strategies -- will significantly improve the individual's ability to accomplish those purposes. Stated another way: through AAC device use, as compared to other available methods of communication, individuals will have the best chance of accomplishing the communicative objectives that will arise in the course of their daily activities.

*2000 Communicative Effectiveness Study*

In July, 2000, the Slesaransky-Poe study was replicated with a much larger number of AAC device users participating. This task was undertaken in direct response to HCFA staff's request for additional outcomes data related to AAC device use. Where Slesaransky-Poe (unpub. 1997) surveyed 45 AAC device users, more than 200 AAC device users participated in the current effort, representing almost a five-fold increase in the volume of data obtained. (Slesaransky-Poe, unpub. 2000).

As in 1997, the *Consumer Survey on Communicative Effectiveness* was used to gather data. Based on the data obtained, the study participants in 2000 were similar to those who participated in the 1997 effort. As in 1997, all the participants were adults. The mean age of the respondents was 41.5, with an age range of 18-87. Thus, the 2000 study population is slightly older, on average, than those individuals who participated in the 1997 study.

Two factors that are significantly broader in the 2000 study population are the range of physical conditions represented and the types of AAC devices that are being used. The 2000 study population included a far more diverse distribution of physical condition diagnoses. In 1997, the 45 AAC device users had 3 conditions: cerebral palsy (91 %), traumatic brain injury (7 %), and stroke (2 %). By contrast, the 204 members of the 2000 study population included individuals with each of those three conditions, 44 %, 10 %, and 3 %, respectively, as well as ALS (19 %), cognitive communication impairments (12 %) , and others (12 %).

Regarding the AAC devices being used, more than 20 different AAC devices were identified by the 2000 study participants, as compared to 7 by the 1997 group. Just as the 1997 study group included individuals who used AAC devices in each of the proposed AAC device code categories, so too did the 2000 study participants. Their distribution among the 3 code categories were as follows:

| | |
|---|---|
| Category I: digitized speech output communication devices: | 6.0 % |
| Category II: synthesized speech output communication devices that require spelling for message production and physical contact direct selection for access: | 18.6 % |
| Category III: synthesized speech output communication devices that permit multiple methods of message production and multiple methods of access: | 71.3 % |

In general, the demographic data about the two study populations are almost identical. The gender distribution in 1997 was 64/36 male/female; for the 2000 study, it was 57/43 male/female. Approximately 61 % of the participants in 1997 completed high school, while approximately 30 % had completed at least 2 years of college. For the 2000 study population, the figures for educational level completed were 56 % and 29 %, respectively.

Small differences exist regarding the daily activities of the study participants. Slightly more than 42 % of the 1997 study group worked either full or part time, as compared to only 23 % of the 2000 study group. Likewise, 15.5 % of the 1997 study group attended school, as compared to 9.5 % of the 2000 group. However, the 1997 study group had far fewer individuals who listed volunteering as their primary daily activity, 4.4 % as compared to 9.5 % of the 2000 study population.

The data describing the means of access for these devices was similar to those reported in 1997. Physical contact direct selection was the overwhelmingly most common access method among both the 1997 and 2000 study groups, with use of the hands and fingers as the most frequent means of contact (73.9 % of the participants in 2000; 53.5 % in 1997). Use of head- and other pointing devices to accomplish physical contact direct selection was a far less frequently used technique (9.0 % of the participants in 2000; 27.9 % in 1997). Electronic aids for direct

selection were used in almost identical percentages (4.5 % in 2000; 4.7 % in 1997). The frequency of use of indirect selection methods were similar (8.0 % in 2000; 13.9 % in 1997).[9]

In addition, the 2000 study participants reported on their duration of device use. The following was reported:

| | |
|---|---|
| > 1 - > 10 years | 58.9 % |
| 0.5 - 1 year | 14.9 % |
| < 0.5 years | 9.9 % |

In regard to the five sections of the *Consumer Survey on Communicative Effectiveness*, the 2000 study population's responses are very similar to those reported by Slesaransky-Poe in 1997 and provide substantial additional support for the positive conclusions about the effectiveness of AAC device use reached in the earlier study.

*Communication Effectiveness in General Communication Activities*

In the General Communication section, the 2000 study population responded as follows:

| **Group** | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 19.91 | 5 to 25 |
| Without device | 11.06 | 5 to 25 |

These data are similar to the data reported by the 1997 study group in the General Communication section:

| **Group** | Mean | Range |
|---|---|---|
| VOCA | | |

9 The data regarding access method for these two study populations also is consistent with data reported elsewhere. Jinks & Sinteff (1995) for example, reported 69 % of AAC device users (24/35) used direct selection, while 31 % (11/35) used switches. Murphy, *et al.* (1995) reported 66 % of the 135 AAC devices her group studied used physical contact direct selection (89/135), while 2 % (2/135) used electronic aid, direct selection, and 33 % (44/135) used switches.

| | | |
|---|---|---|
| With device | 21.73 | 16 to 25 |
| Without device | 12.13 | 6 to 21 |

The data reported by the 1997 and 2000 study populations support the conclusion that with access to and use of AAC devices, individuals with severe communication disabilities are far better able to engage in general communication activities, such as seeking out and providing information, *i.e.*, asking and answering questions; communicating with unfamiliar partners; and communicating with more than one individual at a time.

These data are wholly consistent with the numerous descriptions of the purposes for which AAC devices are recommended and are being used. For example, Bryen, Slesaransky & Baker (1995) described the current general communication activities of 17 individuals who used AAC devices:

> The scope of respondents' current communication was quite broad and varied. . . . All repored communicating with one familiar person and with a group of familiar people. More than 75 % reported that they were communicating with unfamiliar people, talking on the telephone, and writing letters. More than 50 % reported also communicating with a group of unfamiliar people, communicating with someone not in the room, . . . .

These data regarding the general communication opportunities that are improved as a result of AAC device use also match the responses to Question 12 on the survey reported by Marcia Nusgart on September 1, as well as the responses reported in the studies conducted by Mathy, Brown-Herman, and Angelo.

Mathy (1996 ), Mathy and Brune (1993) and Mathy, Yorkston & Gutmann (2000) described the use of AAC devices by individuals with ALS, the majority of whom used multiple methods of communicating. The communicative activities for which AAC devices are used are those that are most effectively and efficiently accomplished with those devices, as compared to other communication methods. These studies show that AAC devices are being used for the same tasks as are described in the General Communication section of the *Consumer Survey on Communicative Effectiveness*.

Likewise, Brown-Herman (unpub. 1999) reported substantial agreement among respondents that as a result of use of the AAC device, the users' messages had become more understandable, that their ability to participate in conversations had increased, and that the number of individuals with whom they communicate had increased.

Angelo (2000) reported similar data regarding general improvement in communicative abilities as a result of use of an AAC device.

*AAC Device Use as Support for Independence*

In the Independence section of the survey, the 2000 study population reported:

| Group | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 21.97 | 6 to 30 |
| Without device | 13.02 | 6 to 30 |

The data reported by the 1997 study group in the Independence section was almost identical:

| Group | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 22.62 | 12 to 30 |
| Without device | 12.73 | 6 to 30 |

The data from both 1997 and 2000 support the conclusion that use of AAC devices can significantly improve the ability of individuals with severe communication impairments, who may also have other severe impairments, to obtain necessary and appropriate care, and to direct the provision of that care both directly, in face to face communication, as well as through the use of the telephone.

In addition, in a more literal sense, these data confirm the truism stated by Bryen, Slesaransky and Baker (1995) that "[i]n order to live independently, a person needs to communicate independently." Access to an AAC device will make it possible for an individual to live on his or her own, or be left alone while a spouse or other family member is at work or engaged in other activities. Mathy, Yorkston & Guttman (2000).

Access to the telephone, one of the factors measured in the Independence section, is frequently cited as a reason why AAC devices are used. (Bryen, Slesaransky, & Baker, 1995; Mathy, Yorkston & Guttman, 2000).

The conclusion from both the 1997 and 2000 Communication Effectiveness survey data that AAC device use increases the independence of individuals with severe communication

disabilities is consistent with other research. Angelo (2000) reported that 56.1 % of the more than 100 respondents to her survey reported "greater independence of the user as a result of using the AAC device." Her report further stated: "72.2 % [of the respondents] reported a more promising future as a result of using AAC devices."

Channer, Ashlock and Levine, (1993) made the same observation in response to use of an AAC device they provided to a 42 year old woman with multiple sclerosis, vision impairment and quadriplegia:

> The portability of the system allows her to not only use the system at home, but also use it in various other settings. *Thus, the system has greatly contributed to increasing M.T.'s overall independence.*

Many other examples of the ability of an AAC device to support increased independence can be found in the literature produced about, as well as produced by AAC device users. One example is supplied by the life experience of Ruth Sienkeiwicz-Mercer. Ms. Sienkiewicz-Mercer, who has cerebral palsy, was unnecessarily institutionalized for years as a result of her inability to communicate. When she was finally provided access to an AAC device, Ms. Sienkiewicz-Mercer was able to secure her discharge from the institution, marry, and then advocate successfully for the institution's closure. (Sienkiewicz-Mercer & Kaplan, 1989).

*AAC Device Use as Support for Productivity*

In the Productivity section, the 2000 study participants reported:

| **Group** | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 7.95 | 2 to 10 |
| Without device | 4.88 | 2 to 10 |

These data are comparable to the data reported by the 1997 study group in the Productivity section:

| **Group** | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 8.93 | 4 to 10 |

| | | |
|---|---|---|
| Without device | 5.11 | 2 to 10 |

These responses most directly confirm the conclusion that AAC device use ***will*** significantly aid their users' ability to meet the communication needs arising in the course of their daily activities. Regardless whether the AAC device users work, attend school, volunteer, or participate in other activities, these resopnses make clear that the ability to participate in these activities is significantly aided by the ability to communicate orally and in an intelligible manner.

These responses are consistent with the conclusions reached in other studies. For example, Bryen, Slesaransky & Baker (1995) reported that their study population of AAC devcie users was able to participate in the following activities:

> Based on the 17 responses, the use of a voice output communication system has substantially helped or will help them with several major life activities. . . . [T]he majority of respondents reported that their current augmentative communication system has helped or will help them substantially in maintaining an income (64.7 %), learning (58.8 %), and communication (82.4 %). . . .

*AAC Device Use as Support for Inclusion*

In the Inclusion section, the 2000 study participants reported:

| **Group** | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 19.36 | 5 to 25 |
| Without device | 11.22 | 5 to 25 |

These data are comparable to the data reported by the 1997 study group in the Inclusion section:

| **Group** | Mean (s.d) | Range |
|---|---|---|
| VOCA | | |
| With device | 20.82 | 10 to 25 |
| Without device | 12.16 | 5 to 25 |

The inclusion and productivity sections of the survey focus on AAC device users' ability to communicate in practical, daily circumstances. The conclusion to be drawn from both the 1997 and 2000 study data are that use of an AAC device can significantly improve the abilities of individuals with severe communication disabilities to maintain their economic, parental and social roles in their families and communities. Use of an AAC device will significantly improve the ability to participate in community-based interactions, including maintaining the household; continuing to exchange information with and provide guidance and counsel to one's spouse, children and grandchildren; and maintaining social relations with friends and extended family. These activities are especially important for individuals with acquired communication impairments. (Fox and Sohlberg, 2000).

These data are consistent with studies conducted by others. Bryen, Slesaransky and Baker (1995) reported on the importance of AAC devices to allow their users to maintain employment, acquire new skills and live independently. The research on individuals with ALS conducted by Mathy and her colleagues reaches similar conclusions about the importance of AAC devices in the community integration of their users.

Angelo (2000) reported that the families of children who received AAC devices from 1985 to 1996, stated overhelmingly that their children have more educational, vocational, and social opportunities; have improved their communication abilities; have achieved an improved quality of life at present and a more promising future; and an increased level of independence.

*AAC Device Users' Overall Satisfaction*

Lastly, in the Satisfaction section, the 2000 study participants reported:

| Group | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 16.45 | 4 to 20 |
| Without device | 8.95 | 4 to 20 |

These data are consistent with the data reported by the 1997 study group in the Satisfaction section:

| Group | Mean | Range |
|---|---|---|
| VOCA | | |
| With device | 17.91 | 8 to 20 |
| Without device | 10.50 | 4 to 19 |

It should be clear from these data that adults with severe communication disabilities who are provided access to AAC devices are significantly more satisfied with their communicative abilities, *i.e.*, of the capability of their AAC devices, and of their abilities to use their devices, to help them meet the communication needs arising in their daily activities.

These data are confirmed by numerous other studies measuring a variety of factors. Jinks and Sinteff (1994), for example, reported two-thirds of the individuals they surveyed were satisfied with their AAC devices.

Brown-Herman (unpub. 1999) reported that as a result of access to AAC devices, 63.5 % of the respondents to her follow up survey (73/115) reported that the AAC device user's general feelling of well-being/state of mind/self-image had improved.

A more recent study by Angelo (2000) of the families of children who received AAC devices from 1985 to 1996, reported that 61.9 % of the respondents (parents) were satisfied with the AAC devices provided, and 77.6 % would recommend the same AAC device to other families. This satisfaction level is further explained by the significant majority of respondents who reported that as a result of using an AAC device, their children have more educational, vocational, and social opportunities; have improved their communication abilities; have achieved an improved quality of life at present and a more promising future; and an increased level of independence.

Bach (1993) made similar findings regarding a study he conducted of individuals with ALS who, like Stephen Hawking, (Hawking, 1995; M. White & J. Gribben, 1992), lost their ability to speak when they required a tracheostomy for respiratory support, and were thereafter provided with an AAC device. He explained the basis for AAC device users' satisfaction with their devices:

> Despite the lack of documented computer-assisted communication benefit on survival, its benefit on quality of life was substantial. All 24 effective users expressed appreciation in dramatic terms for the procurement of their systems. Besides communciating with her family and friends, one patient gainfully used her

system to write prose and poetry for a greeting card manufacturer and to establish a national support group. She wrote that "without the computer I had no means of communication. It is a fantastic uplift. (Without it) tryign to get across the simplest (message) is usually so frustrating (that one) ends up in tears." Another patient observed, "What I (found) hardest to handle (was) my inability to express myself- to communicate. I have been released from prison in a sense. Yet another, "(the system) gave me the freedom to write again, talk to my children. There is nothing greater for a mother than talking to her children. They tell me I sound like a mother again."

* * * * *

"I have decided that I want to live, even tough my life is severely limited. In the midst of it all, life still brings us satisfactions and pleasures. We hope for the best."

Likewise, Jutai and Gryfe (1998) and Jutai (1999) reported on findings of an ongoing study of 55 individuals with ALS who had completed the Psychosocial Impact of Assistive Devices Scale (PIADS), an instrument designed to measure the impact of assistive devices on the quality of life of their users. The study participants reported significant quality of life benefits from use of AAC devices.

Yet another measure of user satisfaction with assistive devices such as AAC devices is reports of non-use. Although HCFA staff has reported concern about the potential for rejection and/or non-use of AAC devices, the available data do not support these fears. Of the 2,310 individuals who had been able to acquire AAC devices following an SLP evaluation and recommendation, Marcia Nusgart on September 1, 2000 reported that only 274 individuals (12 %) needed to change their devices, and that only 372 (16 %) of these individuals stopped using them. Because the latter figure includes individuals who died, this figure overstates the individuals whose non-use was based on dissatisfaction with their devices.

Even stronger are the data reported by Doyle & Yonemori, Brown-Herman and Jinks and Sinteff. Doyle & Yonemori (unpub. 2000) reported at the August 2000 ISAAC Conference about their ongoing study of 27 individuals with ALS. They reported that of the 22 participants who acquired AAC devices, 17 continue to use them and all are satisfied. In addition, two of the individuals who stopped using their devices merely needed changes in their means of physical access.

Brown-Herman (unpub. 1999) reported that only 1.7 % of the individuals who she studied were no longer using the AAC devices provided to them between January 1997 and July 1999. Jinks and Sinteff (1994) reported that less than 7 % of the 45 individuals they studied had stopped using their AAC devices.

These data are significant by themselves to allay HCFA staff concerns about the likelihood of substitution and/or non-use of AAC devices. They are even more significant when compared to other studies reporting about non-use of assistive devices. For example, Day, Jutai and Strong (1999) reported that 59 % of individuals who use contact lenses will abandon them. Phillips (1991) reported that approximately one third of all assistive devices is abandoned. A subsequent survey of families by Phillips and Zhao (1993) reported that 29.3 % of 1,732 assistive devices prescribed for adults with disabilties had been abandoned. In comparison to these non-use rates, the non-use rates reported for AAC devices are significantly lower.

Another measure of both the importance of AAC devices to their users is duration of use. Slesansky-Poe (unpub. 2000) reported that almost 6 in 10 of the individuals who responded had been using their AAC devices for more than a year to more than 10 years.

Another example is provided by the experience of Kimberly Damon. Ms. Damon was reimbursed by Medicare for an AAC device in 1986, before the AAC device national non-coverage decision was published. She continued to use that device, constantly, for eight years. After that device finally stopped functioning, she acquired her current AAC device, in 1996, which also has been put to constant use. Earlier this summer, Ms. Damon's replacement device was approved for Medicare reimbursement by an administrative law judge.

Beukelman and Ansel (1995), in an article specifically cited by HCFA staff in the web-site comments, provide some insights why the expected and actual substitution and non-use rates for AAC devices are low. First, the technology itself is different:

> Over the past 20 years, the features (technological, software) included in AAC systems have changed dramatically. Among the most obvious examples are techniques currently employed to store and retrieve messages and present messages through dynamic display.

In addition, the development and adoption of DEC-Talk as the industry standard speech-synthesizer has resulted in AAC devices being understandable in typical conversational settings, with both familiar and unfamiliar listeners. Both of these factors add to the quality of AAC devices to perform the communicative tasks that their users seek to accomplish.

*Conclusion*

The studies reviewed in this memorandum provide a sampling of the professional literature, published and unpublished, that describe the positive outcomes associated with AAC device use. These studies support the adoption of the proposed Medicare AAC device coverage criteria, as revised, and as submitted to you with the initial responses to the HCFA web-site comments, on June 29, 2000. They demonstrate that:

- individuals with a wide range of neurological/physical condition diagnoses have been evaluated and recommended for AAC devices, have acquired those devices and use them;

- that individuals with all four of the communication impairment diagnoses that are included in the proposed coverage criteria (dysarthria, apraxia, aphasia and aphonia), use AAC devices;

- that AAC devices provide these individuals with the opportunity to meet a wide range of communication tasks, which as a whole comprise the communication needs that arise in the course of their daily activities; and

- that AAC device users are satisfied with the capabilities of these devices and of their ability to use these devices to meet their communication needs, and therefore do not readily seek to change them or stop using them.

The research described above provides a scientific foundation for the prinicple that guides SLPs in all their AAC professional activities. That principle is that "communication is the essence of human life." (Article II, Section I, USSAAC by-laws). As Light (1996) eloquently stated:

> Communication is about touching other people and about having our lives touched by others. Communication is about laughing and arguing, learning and wondering why, telling stories, complaining about what is or what isn't, sharing dreams, celebrating victories. Developing communicative competence allows us to realize the essence of our humanity -- . . . .

As we have explained in the *Formal Request*, in our subsequent conversation and written submissions, and in the discussion above, AAC devices have been developed, they are recommended following comprehensive SLP evaluations, they are covered by third party funding programs, and, they are used, because there are people with severe communication disabilities who are not going to be able to do the things Light describes without them. It is this small population of individuals with severe communication disabilities, whose characteristics are embodied in the proposed Medicare AAC device coverage criteria, for whom AAC devices are needed, and for whom Medicare coverage should be extended.

Lewis Golinker

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