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Dear Dr. Ulrich;

As promised in our recent telephone conversation, I am enclosing two out of the three groups of surveys that we have conducted regarding AAC devices. The third set of surveys should be sent to you next week by Lew Golinker, who will also give you more of a detailed analysis of the surveys.

As you recall, the questions contained in these two sets of surveys are ones to which HCFA staff had requested answers. We gave you copies of this survey at our meeting with Dr. Kang and HCFA staff on July 6, 2000 for your review and comment. We then made several changes to the survey due in response to suggestions from Dr. Laurie Feinberg such as ensuring that the survey focus on individuals who are Medicare eligible rather than children and adding "modify device; change/modify accessories" in question 11 rather than keeping it only as "change device".

The first set of surveys had 17 respondents. They were sent to 26 speech language pathologists who practice in major medical institutions and are leaders in the field of AAC. You will likely recognize many of their names since they were contributors to the Formal Request. These survey responses were prepared either by file review or by the general estimates of their experience over the years.

The second set of surveys had 29 respondents. These surveys were given to speech language pathologists throughout the United States to complete. As in the previous set of surveys, the responses were prepared either by file review or by the general estimates of their experience over the years.

I have included a compilation of the survey results as well as the actual surveys. Please note that for many questions the percentage column does not total 100 %. This reflects the fact that for some questions multiple answers were provided. Also, in question 12, most SLPs responded by referencing the number of patients for whom they recommended AAC devices and not the number that actually acquired them.

After reviewing these 46 surveys, the following observations can be made from the results:

- A significantly larger number of individuals were given speech-language pathology evaluations than were recommended for "high tech" (*i.e.*, voice-output AAC devices). In total, the reporting SLPs (Question 1a) evaluated 8,646 adults, of whom 3,900 were recommended for "high tech" AAC devices (Question 2). That total represents 45 % of all adults who were evaluated. This percentage provides statistical confirmation of the sequential SLP evaluation process that is explained in Section III, Part A of the Formal Request as well as in the flow chart that is in pages 45-46 of the Formal Request. As we stated in that document and in the in-person presentations that we have made to HCFA staff, the SLP evaluation process is intended to identify the individual's communication impairment, its severity, and then, to consider the treatment strategies that will allow the individual to meet his or her individual's daily communication needs. As these figures show, many individuals who are given comprehensive SLP evaluations are not recommended for "high tech" AAC devices, *i.e.*, their daily communication needs can be met by treatment focused on natural communication methods, or through AAC techniques that do not require a voice output communication device.
- The data reported in response to Questions 2 and 4 confirm that there continue to be significant barriers to AAC device access for adults. The data show that of 3,900 individuals recommended for AAC devices (Question 2), only 2,310 were reported to have acquired them. (Question 4). This total represents only 59 % of all individuals for whom voice-output AAC devices were determined to be necessary. The data reported in response to Question 5 identifies funding barriers as the overwhelming reason why the recommended devices were not acquired.
- The data reported in response to Questions 6 and 7 identify the communication impairments that were presented by the individuals who were evaluated, and who were recommended for a voice-output communication device. As we reported in the *Formal Request*, as amended in the Response to the HCFA Web-Site Comments submitted to you on June 29, 2000, the individuals for whom voice-output communication devices will be necessary are individuals with dysarthria, apraxia, aphasia and aphonia. These responses support the inclusion of these communication impairments in proposed Coverage Criterion number 3 and 4, attached to the June 29 Web-Site Comments Response.
- The data reported in response to Questions 8 and 9 identify the range of neurological conditions that were presented by the individuals who were evaluated, and who were recommended for a voice-output communication device. That these responses generated a long list of conditions is consistent with the suggestion made by Dr. Michael Weinrich, that a non-exclusive list of neurological conditions be incorporated into the AAC device coverage criteria. That suggestion was incorporated as Coverage Criterion # 1, which was submitted to you on June 29.
- The data reported in response to Question 9 show that 16 % of individuals who acquired voice output communication devices stopped using them. These data should allay concerns that there is a high percentage of abandonment of AAC devices.
- The data reported in response to Question 11 show the types and frequency of changes that were made to AAC devices and accessories. These data show that few voice output communication device users change their devices; by contrast, it is far more common for

individuals to require a change of device accessories. These data are consistent with the information we have been reporting to you in the *Formal Request* as well as in all the subsequent communications with HCFA staff about AAC devices.

- The data reported in response to Question 12 describe the purposes for which voice output communication devices are used. These data show that these AAC devices are used to accomplish a wide range of daily communication needs, which as expected, mirror the purposes for which Medicare provides speech-language pathology treatment.

Thank you for the opportunity to allow us to provide you with this information. If you have any questions, please do not hesitate to call on me.

Sincerely,

Marcia Nusgart R.Ph.

## SURVEY DATA COMPILATION

Number of years providing AAC evaluations		Number of Respondents	
Less than 3 years:	1		
3-6 years:	3		
7-10 years:	1		
11-15 years:	4		
More than 15 years:	8		
<b>Total Respondents:</b>	<b>17</b>		
Question		Total Number	Percentages
1.	Estimate of cumulative number of individuals (across the age span) you have evaluated for ACC	11155	
1a.	Estimate the cumulative number of adults that are Medicare eligible (developmentally disabled, physically disabled, or over 65 years of age) you have evaluated for AAC interventions	6414	57% of total
<b>Note: For the remainder of the survey please give information only on the adults you have evaluated for AAC devices.</b>			
2.	Estimate of cumulative number of patients recommended for high tech AAC device.	2,409	38% of adults
3.	Of the patients that were NOT recommended for high tech devices what were the top three reasons? Please give estimated percentages in each category. (Note: Not all responses totaled 100%).	4761	
	Reason 1: Low tech system met needs/preferred low tech system	3,549	74%
	Reason 2: Level of intellectual disability	210	4%
	Reason 3: Reluctance to use technology	191	4%
	Reason 4: Decreased cognitive ability	183	4%
	Reason 5: Extremely limited repertoire (borderline illocobonary)	112	2%
	Reason 6: Funding source	105	2%
	Reason 6: Poor support systems at home	57	<1%
	Reason 7: Device characteristics available at time (1991-95)	56	<1%
	Reason 8: Used AAC to support marginally intelligible speech	28	<1%
4.	Of the patients that were recommended for high tech AAC devices, how many actually acquired them? (Note: Not all respondents answered this question.)	1122	
5.	Of those recommended, but that did not acquire them, please give reasons why and %.	1028	

Question	Total Number	Percentages
(i.e., lack of funding, change in condition, rejection of the recommendation) (Note: Not all respondents answered this question.)		
Reason 1: Lack of funding	873	84%
Reason 2: Change in condition/Death	36	4%
Reason 3: Technology not available (in early days of AAC)	20	2%
Reason 4: Uncomfortable with technology	7	<1%
Reason 5: Poor support systems at home	5	<1%
Reason 6: Rejection of recommendation	3	<1%
6. Please estimate percentages of patients that were evaluated by communication diagnosis (dysarthria, apraxia, aphasia)		
Dysarthria	4425	
Apraxia	411	
Aphasia	270	
Other (respondent added)	43	
7. Please estimate percentages of patients that were evaluated and recommended for a high tech AAC device by communication diagnosis.		
Dysarthria	1889	
Apraxia	356	
Aphasia	345	
8. Please estimate percentages of patients that were evaluated by neurological diagnosis. i.e., ALS, MS brainstem stroke, cerebral palsy, Huntington's Disease, Parkinson's Disease)		
Cerebral Palsy	3211	
ALS	1090	
Brainstem CVA/Stroke	433	
Left CVA	168	
Traumatic Brain Injury	119	
Amyotrophic Lateral Sclerosis	56	
MS	48	
Parkinson's Disease	29	
Laryngectomy/Glossectomy	14	
Huntington's Disease	10	

Question	Total Number	Percentages
Aphasia	10	
Neuroleptic Malignant Syndrome	9	
Frederick's Ataxia	9	
Other (Dystonia, Shy-Drager, Alper's, MD, Prog., Supra-nuclear palsy)	9	
Developmental Disabilities	7	
Dementia	4	
Adult DD of unknown origin	4	
Dystonia	3	
Spinal Cord Injury	3	
Olivopontine Cerebellar Atrophy	3	
Muscular Dystrophy	2	
Primary Progressive Aphasia	1	
Basal ganglian degeneration	1	
Spinal Muscle Atrophy	1	
Guillian Barre Syndrome	0	
8a. Please estimate percentages of patients that were evaluated and recommended for a high tech AAC device by neurological diagnosis. (i.e., ALS, MS, Brainstem stroke, cerebral palsy, Huntington's Disease, Parkinson's Disease)		
ALS	1182	
Cerebral Palsy	854	
MS	708	
Brainstem CVA/stroke	384	
Parkinson's Disease	36	
Muscular Dystrophy	30	
Huntington's Disease	22	
Neuroleptic Malignant Syndrome	10	
HT	9	
Frederick's Ataxia	6	
Larynectomy/Glossectomy	4	
Guillian Barre Syndrome	4	
Adult DD of unknown origin	3	
Dementia	1	
Basal ganglian degeneration	1	
Other	1	

Question	Total Number	Percentages
Primary Progressive Aphasia	0	
(Note: Respondent only provided percentages for these conditions.)		
Dystonia		50%
Spinal Cord Injury		100%
Adhesia		20%
Olivopontine Cerebellar Atrophy		40%
9. Of the patients who received a high tech AAC device, estimate how many stopped using the device.	155	
10. Of the patients who stopped using the device, state reasons with estimated %.		
Lack of support/training	64	43%
Change in condition/death	29	19%
Patient needs new device	24	16%
Other	21	12%
11. Since the initial AAC device was acquired, estimate the number of patients that needed to:		
Change device	178	
Modify device (update speech synthesizer, update device software)	233	
Change/modify accessories (access switches, mounting, etc.)	294	
High tech AAC devices are recommended to meet communicative outcomes (needs) that cannot be adequately adequately met with the patient's current communication "system" (e.g., residual speech, light-tech AAC). Using the list of anticipated outcomes below, indicate the number of patients for whom the outcome was considered a primary unmet need to be met by the recommended AAC device.		
12. a. To communicate <u>simple</u> needs/wants to familiar (family, sees person regularly) caregivers.	383	
b. To communicate <u>detailed</u> needs/wants to familiar (family, sees person regularly) caregivers.	1774	

Question	Total Number	Percentages
c. To communicate <u>simple</u> needs/wants to unfamiliar caregivers (e.g., respite worker, nurse in hospital).	1409	
d. To communicate <u>detailed</u> needs/wants to unfamiliar caregivers (e.g., respite worker, nurse in hospital).	1502	
e. To communicate with medical personnel regarding medical care needs and treatment planning.	1109	
f. To engage in conversation with family and friends.	1775	
g. To use the telephone.	803	
h. To maintain employment.	199	
i. To gain employment.	173	
j. To participate in educational activities	299	
k. Other (describe)**	71	
l. Other (describe)		
m. Other (describe)		
**Description:		
Meeting and conversing w/strangers		
To communicate detailed info. To store merchants		
To communicate with other AAC consumers/speech impaired.		
To participate in hobbies		



SURVEY DATA

Total # %

1. Estimate of cumulative number of individuals (across the age span) you have evaluated for ACC interventions	5973	
1.a. Estimate the cumulative number of adults that are Medicare eligible (developmentally disabled, physically disabled, or over 65 years of age) you have evaluated for AAC interventions	2232	

Note: For the remainder of the survey please give information only on the adults included in your response to question 1 a.

2. Estimate of cumulative number of patients recommended for high tech AAC device	1491	
2a. How many were not recommended?	741	

3. Of the patients that were NOT recommended for high tech devices what were the top three reasons? Please give estimated percentages in each category.		
Reason 1. Decreased cognitive abilities	201	27
Reason 2. Poor support systems at home	72	9
Reason 3. Funding Source	45	6
Reason 4. Reluctance to use technology	91	12
Reason 5. Patient lacked motivation	18	2
Reason 6. Could not use device		
Reason 7. Not appropriate		

4. Of the patients that were recommended for high tech AAC devices, how many actually acquired them?	1188	
4a. How many did not acquire them?	303	

5. Of those recommended, but that did not acquire them, please give reasons why and % (i.e. lack of funding, change in condition, rejection of the recommendation)		
Reason 1. Lack of Funding	191	63
Reason 2. Poor support systems at home	51	17
Reason 3. Rejection of the recommendation by patient	34	11
Reason 4. Patient Moved	1	
Reason 5. Change in condition or death	8	3
6. Please estimate percentages of patients that were evaluated by communication diagnosis (dysarthria, apraxia, aphasia):		
Dysarthria	965	43
Apraxia	346	15
Aphasia	307	14
Aphonia	8	

7. Please estimate percentages of patients that were evaluated and recommended for a high tech AAC device by communication diagnosis		
Dysarthria	768	51
Apraxia	274	18
Aphasia	226	15
Aphonia	1	

8. Please estimate percentages of patients that were evaluated by neurological diagnosis (i.e., ALS, MS, brainstem stroke, cerebral palsy, Huntington's Disease, Parkinsons Disease)		
1) CP	669	30
2) ALS	426	19
3) Stroke/Brainstem CVA	253	11
4) Olivopontine Cerebellar Atrophy	153	6
5) Brain Injury	82	4
6) MS	81	4
7) Parkinson	54	2
8) Autism	31	1
9) Huntington's Disease	8	
10) Down Syndrome	8	

11) MD	9
12) Aphasic	1
13) Friederich's Ataxia	1
14) Pick's Disease	1