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February 24, 2000

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Acting Director  
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Dear Dr. Hill:

The most common disabilities affecting the quality of life of persons with cerebral palsy are impaired mobility and difficulty with verbal communication (i.e.: speech). Of these two, people in the disability community consistently rate poor ability with verbal communication as the more serious of the two. Not being able to communicate usually has disastrous effects in the home, the school, the workplace and the community. Also, it is of great importance in interacting with health care providers dealing with the many clinical issues relevant to disability. As important as is the written word, the emotional and contextual richness of verbal communication is the hallmark of all human societies.

In recent years, close collaboration between engineers and speech therapists has resulted in the development of a number of augmentative communication devices that offer the disabled the ability to communicate successfully in nearly any environment. Commercial organizations are now marketing these instruments and they are available in the market place. Innumerable reports from community based studies demonstrate quite clearly the positive impact their use has on the quality of life and independence of those who have difficulty with oral communication. Improvements in instrumentation, particularly in the person-machine interface, continue to be explored; however, the basic instrumentation is now both available and readily usable. As with most useful instruments, new "bells and whistles" are continually being developed, but these are not of great importance to the efficacy of use of the present instruments. The fundamental electronics are already well understood.

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The major problem with the use of communication assistive devices at this time is not their efficacy, but rather their cost. They are not cheap. To a person and family who are already burdened with the often overwhelming costs of maintaining a supportive environment for the disabled, the additional cost of purchasing an augmentative communicative device makes its availability often impossible. The federal program with responsibility for providing health care assistance for persons with disabilities--HCFA--must include the provision of these devices in its list of available services, as it does wheelchairs and walkers for the immobile. Otherwise, persons with a verbal communication disability will continue to be deprived of the opportunity to receive appropriate care and retain their independence.

The United Cerebral Palsy Research and Educational Foundation, as the principle research organization in the private sector for persons with disabilities due to developmental brain damage (e.g.: cerebral palsy), urges that HCFA include augmentative communication devices in its list of approved services.

Very truly yours,



Murray Goldstein, DO, MPH  
Medical Director and COO