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AAC Language Sample Collection: Rights and Privacy

Background

The life experience of people who use AAC (augmentative and alternative communication) is a function of many factors, including communication performance. **People who use AAC have the right to the highest performance communication possible.** Optimized communication performance cannot be assured without the collection and analysis of language samples. Yet, until recently this was rarely done because traditional methods of recording were a time-intensive activity.

Late in the twentieth century, the automatic collection of language samples had begun to contribute to enhanced communication performance for people who use AAC. For around two decades now, AAC systems have incorporated features that permit the review of recent communication content. Use of these features by individuals, families and those who provide services to them has contributed both to improved communication performance of those individuals and also to the development of methods and evidence to support optimizing the communication performance of others.

Today language activity monitoring (LAM) is commonly used for achieving optimized communication performance. The LAM data collection format records the time, method of generating, and content of language events (e.g.: 10:27:05 WPR “would”) providing for a language transcript typical of traditional manual methods of recording. Data can be analyzed to generate quantitative summary measures of communication performance. Although traditional measures can be reported that are routine in clinical practice, the time stamp allows for the reporting of measures specific to AAC system competence. Additional information on LAM and data analysis can be found at

<http://www.aac institute.org/Resources/LanguageSampleCollection/intro.html> and <http://www.aac institute.org/Resources/ProductsandServices/aacperformancereport.html>.

Rights and Privacy

Language samples have been recorded for many decades using manual transcription, audio and video recording means, and automated data logging. In the two decades of such features being available in AAC technology and having been used by many tens of thousands of people who use AAC, not a single documented case of abuse of rights and privacy has been tied to data logging. On the other hand, at least one situation of abuse was detected and corrected through the review of LAM data.

Informed Consent

Informed consent is a necessary prerequisite to any communication disorder service delivery, and should be standard practice by all service delivery practitioners. All individuals with disabilities or parents/guardians sign permissions before assessment and intervention services initiate. Permissions frequently indicate that standardized testing, formal and informal testing, observations and interviews are a part of service delivery or will be used to identify the most appropriate service delivery. Historically, the collection and analysis of language samples has never required additional consideration or exclusion of standard permissions.



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However, since language sample collection has been a routine practice for AAC service delivery for only the past decade, practitioners may specifically note that the collection and analysis of language samples are part of monitoring intervention. Regardless, of whether traditional or automated methods of recording are used in practice, clients and family members have the right to know that clinical decisions are data-driven and they have the right to access the data being collected and analyzed. In addition, when automated methods are used in the natural environment, individuals (or if minors, parents or guardians) should be taught how to turn data collection on and off. A generic informed consent form is available at <http://aacinstitute.org/wp-content/uploads/2014/05/ConsentAndCommunicationForm-ver.2014.pdf>

Past use of audio recording could have been implemented inconspicuously and could have recorded the speech of communication partners and others in the vicinity. Data logging records only the communication of the person who uses AAC. Still, if it is desired to inform others that data logging is being used, that can be done in various ways. Use of a printed notice was proposed in 2002 (Hill, et.al). (Request or download at www.aac institute.org.)

Natural vs. Clinical Environment

For some individuals, communication performance in the clinical environment does not reflect performance in the natural environment. If natural environment performance is to be optimized, then language sample collection in the natural environment must be done. However, the decision about the extent of recording should be left between the client and clinician. Rarely should the need for 24/7 recording be necessary, and all automated methods of recording can be turned on and off at will. Further, any block of time can readily be deleted from any recording.

Professional Accountability and Funding

AAC professionals want to be able to demonstrate that their work is producing desired results and is justified. They also want to assure that therapy goals are appropriate and that progress toward goals is being made. Quantitative measurement of communication performance is one component of data-driven clinical decisions and a professional service delivery program.

Funding parties have a vested interest in assuring that their resources are being properly invested. Inclusion of LAM data has already become a requirement of one or more parties funding AAC systems and services in the United States.

Consumer Choice and Summary

In the end consumers have the right to choose. However, their choice should be informed. They must know that assurance of optimized communication performance (assurance of optimized life experience) can only result from the collection and analysis of language samples.

The collection and analysis of language samples is part of the very foundation of optimizing communication performance for people who use AAC. It can be implemented in a manner that both respects rights and privacy and offers individuals an optimized life experience.

Reference

Hill, K., Romich, B., Botten, S. (2002). Rights and Privacy in AAC Evidence-Based Clinical Practice. In *Proceeding for Technology and Persons with Disabilities, California State University, Northridge (CSUN)*. Los Angeles, CA.