Information Package

on

Augmentative and Alternative Communication (AAC)

For Socially Valued Adult Roles

Joseph Lane
**POLICYBRIEF**

**EMERGENCY SPEAKING:**

Helping citizens who cannot speak communicate during emergencies.

A Federally-sponsored project to address a need for vocabulary and symbol sets among adults who use Augmentative and Alternative Communication (AAC) devices.

### INTRODUCTION

**Setting the scene**

School-aged children and youth who cannot speak are supported by professionals in the acquisition and use of speech generating devices, along vocabulary and symbol sets appropriate to their age and roles. However, there are no equivalent supports for adults, particularly those whose disability includes learning delays that limit their ability to spell. These adults find themselves without the vocabularies and symbol sets appropriate to adult roles such as communicating information about an emergency situation affecting themselves or others. This issue is relevant to government officials or agencies in the context of communication about a natural disaster, a health epidemic, a criminal act, a public transportation accident, or a threat to homeland security.

**The Research Study**

Professor Diane Bryen, PhD conducts research in the field of Augmentative and Alternative Communication (AAC). Her studies demonstrated that commercially-available AAC vocabulary and symbol sets did not represent the needs of persons participating in adult life roles such as higher education, employment, victim of crime or emergency situation, transportation, independent living and personal intimacy. Dr. Bryen then involved AAC users in the creation and validation of appropriate vocabulary and symbol sets for such adult roles. The resulting materials are freely available for downloading and use by others from a public website. They also serve as examples for the creation of further vocabularies and symbol sets appropriate to adult citizens (e.g., politics, community affairs).
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<th>Citation</th>
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<td>Dr. Bryen’s work appeared in the following peer-reviewed journal article: Bryen, DN (2008), <em>Augmentative and Alternative Communication</em>, 24, 4, 294-301</td>
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<th>Participants</th>
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<td>A total of 61 individuals participated in this study: 27 who used AAC and 34 participants who were professionals or family members. AAC users were included if they were 18 years of age or older, and within the prior two years had been involved in, activities related to any of the study's six adult roles: College life; Intimate relationships; Crime reporting; Managing personal assistant services; Managing health care; and Managing transportation. Participants who used AAC lived across the United States, ranged in age from the late 20s to over 60 years old; represented a variety of ethnic and educational backgrounds and disabilities (e.g., developmental, acquired disability); and used a variety of AAC devices. All were paid for participating in the study.</td>
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<th>Procedure</th>
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<td>In order to identify the vocabulary sets needed to fulfill adult roles, participants were organized into electronic discussion groups based on common interests. Electronic mailing seemed particularly well suited for individuals who rely on AAC, given that most are slow in communicating. The asynchrony of electronic mailing lists creates no inherent barriers to brainstorming and reflecting on other's responses, in contrast to face-to-face brainstorming or focus groups, where speed of output may be needed. After several weeks of on-line discussion within each electronic group, a comprehensive unduplicated vocabulary set was formed for each category. These vocabulary sets were re-introduced to the electronic groups so they had an opportunity to add missing vocabulary. This process was repeated for the vocabulary set for each of the six socially valued adult roles.</td>
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<th>Data Analysis</th>
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<td>Almost 3,000 words were generated by the participants, ranging from 287 words for the Managing Transportation set to 799 words for the Reporting Crime set. The overall mean for the six vocabulary sets was 463 words. A complete alphabetical listing of the vocabulary identified for each of the six socially valued adult roles is posted at: <a href="http://www.disabilities.temple.edu/aacvocabulary">http://www.disabilities.temple.edu/aacvocabulary</a>.</td>
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The next step was to determine the extent to which the words in these vocabulary sets were already represented in the vocabulary/symbol sets contained in the three leading commercially available AAC devices: Prentke Romich Unity 128(Unity 128™), Mayer-Johnson Picture Communication Symbols™ (PCS™), and Dynavox Systems Dynasyms™ (Dynasyms™). A discrepancy analysis was performed for each commercial symbol system independently by two different raters. The mean overall inter-rater agreement was 83% across the 18 data sets (six vocabulary lists x three commercial symbol sets). Inter-rater agreement ranged from 56% for PCS™ (reporting crime) to 99% for Dynasyms™ (personal assistant and transportation).

Study Results

Overall, the mean percent of adult vocabulary that could be created by the three commercial symbol sets ranged from 44% for managing transportation to 69% for managing health care. Across all six adult vocabulary sets, just over half (55%) of the words could be represented through the three commercial symbol sets. For each commercial symbol set, the mean percentage was:

- 68% for Mayer-Johnson's PCS™ (51% college to 81% crime reporting);
- 58% for Dynavox's Dynasyms™ (45% sexuality to 74% health care);
- 40% for Unity 128™ (31% transportation to 54% health care).

None of the commercial symbol sets contained symbols (or combinations of symbols) to represent more than 81% of the vocabulary generated through the study to represent communication needed in adult roles. This exceptionally high percentage of vocabulary for crime reporting in the Mayer-Johnson system (81%) is attributed to a study that created about three hundred symbols on sexuality and reporting sexual abuse to the criminal justice system.

Study Outcomes

1. Symbol Sets for Six Adult Roles

As a result of the study, Dr. Bryen created six symbol sets corresponding to the six adult vocabularies generated by the study participants. All six sets are freely available on the project’s website: [http://disabilities.temple.edu/aacvocabulary/index.shtml](http://disabilities.temple.edu/aacvocabulary/index.shtml)
Dr. Bryen conducted and published a follow-up study cited as: Bryen, DN (2009). “Communication during times of natural or man-made emergencies.” *Journal of Pediatric Rehabilitation Medicine*, 2, 2, 123-129. This peer-reviewed article can be accessed at: [http://iospress.metapress.com/content/8879700131u57vj6/](http://iospress.metapress.com/content/8879700131u57vj6/)

The prior work in the AAC community had identified yet another need for a vocabulary set, which became particularly important in light of communication problems identified in the aftermath of Hurricane Katrina in New Orleans. Effective communication in times of man-made or natural disasters were determined to be key to effective emergency preparedness, response, and management. However, those with significant communication disabilities are at particular risk because they may not have the vocabulary needed to effectively communicate. Similarly, emergency first responders may not know how to communicate with people with complex communication needs.

Dr. Bryen’s follow-up study generated a new vocabulary set for communicating in times of emergency. It was developed based on the structured input of both people who use AAC, and professionals who work as first responders in times of emergencies. This new set is designed for AAC users, and to provide education and support to emergency responders, hospitals, school, work and community disaster preparedness offices, and policy makers.

The **Emergency Communication 4 All Aids** can be accessed or downloaded at [http://disabilities.temple.edu/aacvocabulary/e4all.shtml](http://disabilities.temple.edu/aacvocabulary/e4all.shtml). They include:

- a full Emergency Preparedness vocabulary set
- an emergency picture communication board
- an emergency communication letter and word communication board

**Tips for Communicating with Someone Who Needs Assistance** can be downloaded at: [http://disabilities.temple.edu/aacvocabulary/e4allTips.shtml](http://disabilities.temple.edu/aacvocabulary/e4allTips.shtml)
We foresee the application of these adult vocabularies as a resource for various situations outside of as well as within traditional service areas. For example, the emergency communication boards that were developed (see Emergency Preparedness vocabulary set) can be used for communication related to emergency and safety by individuals who use AAC, and by those who are non-English speakers. These boards include the Emergency Communication 4 ALL—Picture Board for English, Spanish, and Haitian Creole language users, and the Emergency Communication 4 ALL—Letter and Word Communication Aid board for English and Spanish users. The communication boards and tips related to communicating with those who need assistance can be downloaded at no cost from the Institute on Disabilities website at http://disabilities.temple.edu/aacvocabulary/e4all.shtml#index. The full communication board can be found in the appendix.

The AAC-RERC and the United States Association for Augmentative and Alternative Communication (USAAC) sponsored the development and posting of needed information both for people with complex communication needs and for first responders. You can view this important information by going to http://aac-rerc.psu.edu/index-46053.php.html.
Example: Emergency Communication 4 ALL—Picture Board\(^1\) in English

\(^1\) The Picture Communication Symbols ©1981–2009 by Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission. Boardmaker® is a trademark of Mayer-Johnson LLC.
Example: *Emergency Communication 4 ALL—Picture Board* in Spanish