



Information Package
on
**Augmentative
and Alternative
Communication
(AAC)**

For Socially Valued Adult Roles

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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 with 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).

Citation	Dr. Bryen's work appeared in the following peer-reviewed journal article: Bryen, DN (2008), Augmentative and Alternative Communication , 24, 4, 294-301
Participants	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.
Procedure	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.
Data Analysis	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: http://www.disabilities.temple.edu/aacvocabulary .

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 128TM), Mayer-Johnson Picture Communication SymbolsTM (PCSTM), and Dynavox Systems DynasymsTM (DynasymsTM). 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 PCSTM (reporting crime) to 99% for DynasymsTM (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 PCSTM (51% college to 81% crime reporting);
- 58% for Dynavox's DynasymsTM. (45% sexuality to 74% health care);
- 40% for Unity 128TM (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>

2. Emergency
Preparedness &
Communication

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/>

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.

Vocabularies for Free
Access & Download

The **Emergency Communication 4 All Aids** can be accessed or downloaded at <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>

Vocabulary Set	Resources	Websites
Emergency Preparedness	Full Emergency Preparedness vocabulary set	http://disabilities.temple.edu/aacvocabulary/EMERGENCY_FULL.shtml
	Emergency Communication4ALL Picture Communication Aid English / Spanish - download PDF	http://disabilities.temple.edu/aacvocabulary/e4all.shtml
	Emergency Communication 4 ALL Letter and Word Communication Aid English / Spanish - download PDF	http://disabilities.temple.edu/aacvocabulary/e4all.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 Board¹** in English

Emergency Communication 4 ALL								Picture Communication Aid							
FREE SPACE (for your custom message)								I can't speak but I can hear and understand you.				My technology needs to be charged.			
								My vital information is on the back on this page.				Please contact my family.			
MY NAME IS	I, me, my	Bleed	Infect	Allergy	Disability	Help	Bathroom	Ask me questions if you need to, but please wait patiently for my replies.							
WHO	You, yours	Broken	Need/Want	Blanket	Disaster	Home	Walker	I will point to where I hurt. →							
WHERE	She, her, hers	Burn	Rescue	Clothes	Emergency	Hospital	Wheelchair	0	1	2	3	4			
WHAT	He, his, him	Choke	Spell	Cold	Family	Sick	Wind	5	6	7	8	9			
WHEN	They, them, their	Communicate	Talk	Damage	Fire	Pets	Worried	A	B	C	D	E			
WHY	We, ours	Evacuate	Understand	Danger	Flood	Shelter	Worse/Worst	F	G	H	I	J			
HOW	YES	Hurt/Injure	Wait	Communication Device	Heat/Hot	Seizure	NO	K	L	M	N	O			
								P	Q	R	S	T			
								U	V	W	X	Y			
								Z	?	.	!!	SPACE			

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Example: **Emergency Communication 4 ALL—Picture Board¹** in Spanish

COMUNICACIÓN DE EMERGENCIA PARA TODOSMateriales de Comunicación con Imágenes

ESPACIO VACÍO (para su mensaje personal)

No puedo hablar pero si lo puedo oír y entenderlo.

Necesito cambiar mis máquinas.

Mi información importante está en el reverso de esta página.

Por favor póngase en contacto con mi familia.

Hágame preguntas si necesita hacerles, pero por favor tenga paciencia y espere mi respuestas.

Yo señalaré donde me duele. →

0	1	2	3	4
5	6	7	8	9
A	B	C	D	E
F	G	H	I	J
K	L	M	N	O
P	Q	R	S	T
U	V	W	X	Y
Z	?	.	!!	Espacio

ME LLAMO	Yo, mi, mío	Sangrar	Infectar	Alergia	Discapacidad	Ayuda	Baño
¿QUIÉN?	Tú, tuyo	Quebrado	Quiero o Necesito	Frazada	Desastre	Hogar	Andador
¿DÓNDE?	Ella, de ella, suya	Quemar	Rescatar	Ropa	Emergencia	Hospital	Silla de ruedas
¿QUÉ?	El, suyo, él	Ahogarse	Deletrear	Frio	Familia	Enfermo (a)	Viento
¿CUÁNDO?	Ellos, les, de ellos	Comunicarse	Hablar	Daño	Fuego	Mascotas	Preocupado
¿POR QUÉ?	Nosotros, nuestro	Evacuar	Entender	Peligro	Inundación	Refugio, Albergue	Peor. El peor
¿CÓMO?	SI	Herir, lastimar	Espera	Aparato de comunicación	Calefacción, Caliente	Ataque	NO

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