



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

For Socially Valued Adult Roles

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EXECUTIVE SUMMARY

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PRODUCT NEED AREA

Individuals who use Augmentative and Alternative Communication (AAC) and their families have new expectations for life after high school, including attending college, becoming employed, managing personal assistance services and transportation, and having intimate relations. Augmentative and Alternative Communication (AAC) strategies and products are needed assist people with severe communication disabilities to participate more fully in these social roles. Many products and resources are available that address the needs of children up to the age of 19 who require AAC; ***however, the adult population over the age of 19 has been neglected.*** The vocabulary needed to support these socially-valued adult roles is frequently not available in pre-programmed devices or in commonly used visual symbol systems.

PRODUCT SOLUTION

A national researcher, Diane Bryen, PhD, of Temple University has recognized this product void and developed solutions to rectify the situation. Working with people with disabilities, caregivers, and clinicians, the researcher has produced eight evidence based vocabulary sets that are meaningful in situations and environments encountered by adults, including:

VOCABULARY SETS

- College Life Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/COLLEGE.shtml>
- Emergency Preparedness Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/EMERGENCY.shtml>
- Employment Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/EMPLOY.shtml>
- Intimacy and Sexual Relations Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/SEXUALITY.shtml>
- Reporting or Telling about Being a Victim of a Crime Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/CRIME.shtml>
- Health Care Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/HEALTH.shtml>
- Personal Assistance Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/ASSIST.shtml>
- Transportation Vocabulary Set
<http://www.temple.edu/instituteondisabilities/aacvocabulary/TRANS.shtml>

The links provided above next to the vocabulary sets are links to each vocabulary set's page, and on that page there are links to the symbol sets and full vocabulary lists.

Graphic symbols or icons are frequently paired with vocabulary words on AAC devices to aid with proper word selection. Where possible, for each vocabulary set, graphic symbols and icon sequences in two widely used symbol sets are provided to correspond with each needed vocabulary item. These symbol sets are as follows:

- Unity 128 icon sequences,
- Picture Communication Symbols (PCS), and
- Dynasyms

The Temple University website that would further explain this work is: <http://disabilities.temple.edu/>

CONSUMER DRIVEN

Sixteen online focus groups were used to generate needed words for each of the eight vocabulary sets. From these eight sets, discrepancy analyses were conducted to determine whether graphic symbols or symbol combinations in each of the two commonly used symbol sets could represent those words. All missing vocabulary for each of the eight vocabulary sets is available for transfer to manufacturers with the hope that new symbols or symbol sets would be developed where needed. In the case of Unity 128, a long time user of Unity 128 developed many of the icon sequences.

TARGET MARKETS / MARKET SIZE

According to the American Speech-Language - Hearing Association (ASHA) several studies suggest that 8 to 12 people per 1000¹ experience severe communication impairments that require augmentative and alternative communication (AAC) aids. Based on an August 2008 US Census report², the projected US population in 2010 will be over 310,234,000. Of that population number 27% or 84,151,000 will be age 19 and under. The projected population number for those over the age of 19 will be 226,083,000.

Taking into account the ASHA referenced studies mentioned above on the percentage of the population requiring AAC aids, in 2010, 2,481,872 to 3,722,808 people in the US will require AAC aids. Seventy-three percent of that population or, 1,811,767 to 2,717,650, will be over the age of 19 in 2010. In 2015, the projected number of adults requiring AAC aids is expected to increase to between approximately 1,900,000 to 2,850,000, and in 2020 to between approximately 2,000,000 to 3,000,000.

It is for this population of adult AAC users that comprehensive vocabulary lists and symbols are needed in today's market.

¹ <http://www.asha.org/research/reports/aac.htm>

² Table 12: Projections of the Population by Age and Sex for the United States: 2010 to 2050 (NP2008-T12), Source: Population Division, U.S. Census Bureau, Release Date: August 14,2008

BUSINESS OPPORTUNITY FOR AAC ADULT VOCABULARY

Based on our research, currently there are very few AAC vocabulary lists for adults, only children. Comprehensive vocabulary lists for socially valued adult roles will ease AAC users stress when communicating. Based on the need for this product, there is an opportunity for a company to pursue SBIR or other federal agency funding to create symbols for each of the vocabulary sets thereby transforming the new socially valued adult vocabulary sets into products such as the Emergency Preparedness Board. We foresee any company wishing to undertake this effort as having viable marketing outlets for distribution through the organizations listed below (Marketing Strategy section). In addition, as a secondary market, clinicians could also use the vocabulary sets and newly created symbols to modify current adult AAC user's devices enabling them with newfound communication abilities.

INTELLECTUAL PROPERTY

Temple University permits the use of the Vocabulary Sets located on its Institute on Disabilities Website by organizations interested in pairing the vocabulary with symbols and developing picture communication boards for use by the adult AAC population. Any works or products incorporating these Vocabulary Sets must reasonably acknowledge the contributions made by Diane Bryen, Temple University's Institute on Disabilities, The Rehabilitation Engineering Research Center on Communication Enhancement, and the National Institute on Disability Rehabilitation Research. In addition, the picture communication symbols used on the picture board 'Emergency Communication 4 ALL' are used with permission from DynaVox-Mayer Johnson. Permission must be obtained for use of academic papers authored by Diane Bryen.

MARKETING STRATEGY SUGGESTIONS

- College Vocabulary Set - market to university offices through Association on Higher Education and Disability (AHEAD) and other university organizations
- Emergency Preparedness Vocabulary Set - market to cities disaster preparedness offices; market to hospitals, market to first responders; market to FEMA; market to CIL's
- Employment Vocabulary Set - market to state employment offices; market to CIL's
- Intimacy and Sexual Relations Vocabulary Set - market to pharmacies; market to CIL's
- Reporting or Telling about Being a Victim of a Crime Vocabulary Set - market to city, county and state police departments; market to CIL's
- Health Care Vocabulary Set - market to hospitals; physician's offices; pharmacies; CIL's
- Personal Assistance Vocabulary Set - market to health care aid organizations – those who hire and place aides; market to CIL's
- Transportation Vocabulary Set - market to transportation authorities; market to CIL's

**AUGMENTATIVE
AND ALTERNATIVE
COMMUNICATION (AAC)
FOR SOCIALLY VALUED
ADULT ROLES**

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) FOR SOCIALY VALUED ADULT ROLES

TECHNOLOGY DESCRIPTION

Augmentative and Alternative Communication (AAC) can assist individuals in communicating with society. Augmentative communication is comprised of vocabulary lists that the disabled use to assist with communication. Many vocabulary lists offered are sufficient for younger users; however, are insufficient for adults.

According to Diane Nelson Bryen and Bonnie M. Moulton³, individuals who use AAC and their families have new expectations for life after high school, including attending college, becoming employed, managing personal assistance services and transportation, and having intimate relations. However, the vocabulary needed to support these socially-valued adult roles is frequently not be available in pre-programmed devices nor in commonly used visual symbol systems.

Vocabulary is needed to participate in eight socially-valued adult roles: college life; emergency preparedness; employment; sexuality, intimacy, and sex; reporting crime and abuse; managing personal assistance services, managing health care; and using transportation.

Bryen and Moulton inform that sixteen online focus groups were run and data collected was used to generate needed words for each of the eight vocabulary sets. From these eight lists, discrepancy analyses were conducted to determine whether graphic symbols or symbol combinations in each of the two commonly used symbol sets could represent those words. All missing vocabulary for each of the eight vocabulary sets was transferred to manufacturers with the hope that new symbols or symbol sets would be developed where needed. In addition, where possible, for each vocabulary set, graphic symbols and icon sequences in two widely used symbol sets are provided to correspond with each needed vocabulary item. These symbol sets are as follows: Unity 128 icon sequences, Picture Communication Symbols (PCS), and Dynasyms.

VOCABULARY SETS

- **College Vocabulary Set:** College life is often demanding, stressful, hard work, and lots of fun. The purpose of this vocabulary set is to support the communication needs of individuals who rely on AAC and who are attending college. The vocabulary set selected is not based on a specific college class (e.g., Art History 101, American Literature 103), but for more effective communication in a wide range of college activities (e.g. registration, academics, extracurricular college life as well as the very important social component of college life such as housing, transportation within the college, disability resources and accessibility).

This vocabulary set was developed with the input of eight individuals who rely on AAC and who are either currently attending college or who have attended college within the past 5 years. In addition, non-disabled students and professionals involved in college life as either faculty, advisors, or disability resources persons also participated in generating needed vocabulary.

³ (<http://grants.nih.gov/grants/guide/rfa-files/RFA-HD-02-002.html>)

- **Emergency Preparedness Vocabulary Set:** Effective communication in times of man-made or natural disasters is key to effective emergency preparedness, response, and management. However, people with disabilities, especially 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.

The Rehabilitation Engineering Research Center (RERC) and the United States Association for Augmentative and Alternative Communication (USAAC) have 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-lerc.psu.edu/index-46053.php.html>.

In addition, needed vocabulary for communicating in times of emergency is available. As with other vocabulary sets, vocabulary for communicating in times of emergency were developed based on the structured input of both people who use AAC, and professionals who work as first responders in times of emergencies.

- **Employment Vocabulary Set:** Successful employment requires more than skills and knowledge specific to a particular job. Most employers suggest that work-related skills such as punctuality, reliability, problem solving, and YES communication are also critical. Whether you have to interact with your boss, co-workers, supervisor, or customers, effective and efficient communication is essential. This places unique demands on individuals who rely on AAC technologies, especially where pre-programmed vocabulary and corresponding symbols are not available on the communication device or where the individual cannot effectively and efficiently spell needed words. Quick access to the needed employment-related vocabulary and its corresponding graphic symbols should be helpful.
- **Intimacy and Sexual Relations Vocabulary Set:** Intimacy is closely tied to communication. Whether you are telling your partner that he looks handsome or she smells wonderful or advising your partner about how to best arouse you, communication is essential. According to the University of Michigan Health system⁴, an intimate relationship is one in which you: Pay attention to your partner, share ideas and thoughts, share feelings with each other without fear, try to understand why you and your partner behave as you do.

You can communicate in many ways: Words (what you say and what you do not say in phone calls, in person, in writing), gestures (turning away from your partner, nodding your head, showing that you are listening), facial expressions (smiling, frowning, looking disgusted), and/or touch (hugs, holding hands, sexual intimacy).

Research has shown that the quality of your relationship is directly related to the quality of your communication skills. For individuals who use AAC, having “the right words at your finger tips [or your AAC device]” can make all the difference in your relationships.

- **Reporting or Telling about Being a Victim of a Crime Vocabulary Set:** People with disabilities, especially those who have significant communication disabilities, are often victims of crime or abuse. In fact, recent research suggests that they are more likely than their nondisabled peers are to be a victim of a crime. There are many reasons for this high incidence

⁴ (www.med.umich.edu/1libr/wha/wha_verb_bha.htm)

of criminal victimization, chief among them is the belief by perpetrators that the victim will not tell; and if the victim does try to tell, she will not be understood and therefore not be believed. Many victims of crime who rely on AAC devices do not have the vocabulary needed to describe what happened to them. As a result, they fail to tell or report a crime. Failing to tell someone you trust what happened to you and who did it, or failing to report the crime to the police reinforces the perpetrator's belief that he or she can continue to hurt you. The following vocabulary should help you tell others if you have been a victim of a crime or abuse. By telling or reporting, you are improving your personal safety.

- **Health Care Set:** Visiting a doctor's office can make you nervous, impatient, or even scared. You may have only a few minutes with your health care provider. If you do not have the vocabulary you need to describe your symptoms or ask precise questions about your health care, you are likely to jeopardize your health. The vocabulary provided here should enhance your effectiveness and efficiency when communicating with your doctor or other health care professional.
- **Personal Assistance Set:** For many individuals who use AAC devices, personal assistance services (also known as attendant care services) will be key to participating in many adult roles such as college, employment, traveling, and even managing health care. In order to get the services and supports that you need and prefer, you will need to communicate precisely what you want. For example, if you want to be transferred from your bed to your wheelchair, you will need to tell your assistant exactly how you want it done so that it is done safely and comfortably. Without the vocabulary needed to effectively direct your personal assistance supports, it is likely that supports will not be provided in the way you want. The vocabulary and graphic symbols found in this vocabulary set should be helpful in effectively communicating with your personal assistant.
- **Transportation Set:** Traveling using a variety of modes of transportation depends on how accessible and reliable that mode of transportation is. This is especially true if you use mobility technology in addition to communication technology. Whether you use a bus, a train or a plane, much of your independence, comfort, and safety will depend on how effectively you can (1) communicate where you want to go; (2) ask for directions if you are lost; or simply (3) chat with the person sitting next to you. The vocabulary in this set along with the symbol sets should enhance your transportation-related communication.

APPENDICES

APPENDICES

Copies of the following research articles were provided in this section with previous permission from the publisher:

- **Article 1**

“Bryen, D. & Moulton, B. (1998). Why “Employment, independence, marriage and sexuality? Because ... We want it all!” *Proceedings of the 3rd Annual Pittsburgh Employment Conference for Augmented Communicators*, Volume 6, Pittsburgh, PA: SHOUT Press. Reprinted in (1999). *Issues in Special Education and Rehabilitation*, 14(2). Also reprinted in Hebrew in ISAAC-Israel (2001).”

- **Article 2**

“Bryen, D.N. (2008). Vocabulary to Support Socially-Valued Adult Roles. *Augmentative and Alternative Communication*, 24(4), 294-301.”

- **Article 3**

“Bryen D. N. (2009). Communication during times of natural or man-made emergencies. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach* 2, 123-129.”

- **Sample Board**

- **Sample Bookmark**