<u>RESNA Suggested Procedures and Guide to Support the Use of</u> <u>Speech Generating Devices as Augmentative and Alternative Communication</u>

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ABSTRACT This document, *approved by the Rehabilitation Engineering & Assistive Technology Society of North America (RESNA) Board of Directors in ????,* shares relevant literature and was developed as guidance to support the best outcomes for individuals who might benefit from the use of speech generating devices and services.

INTRODUCTION

This white paper was written by the Special Interest Group (SIG) for Communication Technologies and Computer Access (CTCA) of the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA).

It was developed as guidance to help improve outcomes for individuals needing Speech Generating Devices (SGD) and incorporates input from many professionals, both members and nonmembers of the CTCA SIG.

The purpose of this document is to share accepted clinical standards as well as provide evidence from the literature supporting the application of an SGD as a Communication Aid, to assist practitioners in decision making, and implementation. It is not intended to replace clinical judgment related to specific client needs.

Implementing an SGD into a client's life is a multifaceted, interdisciplinary project. This paper can be used as a guide for the team to consider when navigating these tasks.

This document was developed based on the belief that everyone has a right to communicate, and that an SGD may be an essential component of someone's AAC system.

"Communication is the essence of human interaction and learning. The nature of communication is dependent on interaction between two or more individuals and understanding is constructed through that interaction. Communication is a basic human right and essential to our quality of life as a social species. As human beings, we use communication to: relate to others, socially connect, greet, call attention, share feelings, express an opinion, agree, disagree, explain, share information, question, answer, tease, bargain, negotiate, argue, manipulate, compliment, comment, protest, complain, describe, encourage, instruct, provide feedback, show humor, discuss interests, be polite, make friends, express interest or disinterest, etc." (Source: https://www.isaac-online.org/english/what-is-aac/what-is-communication/) 11/11/13

KEYWORDS

Augmentative and Alternative Communication (AAC) Assistive Technology Professional (ATP) Speech-Generating Device (SGD) Speech Language Pathologist (SLP)

What is AAC?

Augmentative and Alternative Communication

The International Society for Augmentative and Alternative Communication (ISAAC) defines AAC as follows: "AAC is a set of tools and strategies that an individual uses to solve every day communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc. Everyone uses multiple forms of communication, based upon the context and our communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message."

(Source: https://www.isaac-online.org/engish/what-is-aac/) 11/11/13

Beukelman, Garrett, and Yorkston (2007, p.4) offer a slightly different definition: "The general definition for AAC used in most legal, educational, and funding activities is similar to the following: AAC is needed by individuals with such complex communication limitations that they are unable to meet their daily communication needs through natural speech (and/or language) (Beukelman & Mirenda, 2005). This definition does not require that the individual be unable to write or speak at all but rather that the person's communication needs cannot be met without support. For some people AAC is needed to communicate a large portion of their needs; others might require AAC only in some contexts or with some listeners."

Beukelman, D.R., Garrett, K.L. & Yorkston, K.M. (Eds.). (2007) *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co.

Beukelman, D.R., & Mirenda P. (Eds.). (2005) *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (3rd ed.). Baltimore: Paul H. Brookes Publishing Co.

What is an ATP?

Assistive Technology Professional

The initials "ATP" refer to one who has earned national certification from the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), a professional organization that promotes the health and well-being of persons with disabilities through technology.

An Assistive Technology Professional is a service provider who analyzes the technology needs of consumers with disabilities and helps users select and use adaptive devices. ATPs work with clients of all ages with every type of cognitive, physical, and sensory disability. The solutions provided, whether low- or high-tech, are usually designed to enhance communication, mobility, and access to computers and educational materials.

(Source: <u>http://assistivetechnology.about.com/od/DisabilityOrganizations/f/What-Is-An-Assistive-Technology-Professional.htm</u>) 4/3/2014

The ATP certification recognizes demonstrated competence in analyzing the needs of consumer with disabilities, assisting in the selection of appropriate assistive technology for the consumer's needs, and providing training in the use of the selected device(s). The ATP is a generalist certification that covers a broad range of Assistive Technology. Assistive Technology areas addressed by the program include:

Seating and Mobility, Augmentative and Alternative Communication (AAC), Cognitive aids, Computer access, Electronic Aids to Daily Living (EADL), Sensory, Recreation, Environmental modification, Accessible transportation (public and private), Technology for learning disabilities. (Source: <u>http://resna.org/certification/becoming-certified.dot</u>) 4/3/2014

What is an SGD?

Speech Generating Device

A speech generating device (SGD), also referred to as voice-output communication aids (VOCA), are electronic devices that allow the user to select messages to be spoken aloud, thereby assisting people who are unable to use natural speech to meet the majority of their communication needs.

(Source: http://bridgeschool.org/transition/multimodal/sgd.php) 3/5/14

The term SGD was coined by Medicare in the year 2000 when a major change in coverage for SGDs was implemented by Centers for Medicare and Medicaid Services (CMS). (Medicare Funding of AAC Technology - Frequently Asked Questions and Answers (FAQs) Source: <u>http://aac-rerc.psu.edu/index.php/pages/show/id/23</u>) However, SGDs existed prior to the year 2000, in fact going back to the early 1970s when they became commercially available as Augmentative and Alternative Communication (AAC) devices. Research in the AAC – SGD field has been extensive and there are many terms referring to speech devices that speak for people who cannot use their own natural voice, including, but not limited to, Voice Output Communication Aid (VOCA), Communication Aid (CA), Electronic Communication Device (ECD), and Communication Boards.

A Speech-Generating Device (SGD) is considered as Durable Medical Equipment (DME) by the insurance industry. (See: National Coverage Determination (NCD) for Speech Generating Devices

(Source : <u>http://cms.hhs.gov/medicare-coverage-database/details/ncd-details.aspx?NCDId=274&ver=1</u>) 3/20/14

In this paper, we shall adopt the term SGD - to reference Speech Generating Devices

What is an SLP?

Speech Language Pathologist

"The American Speech-Language-Hearing Association endorses the official title speechlanguage pathologist (SLP) for those qualified individuals who diagnose, prognose, prescribe for and/or remediate speech and/or language disorders."

(Source: http://www.asha.org/policy/RP1976-00129.htm) 3/5/14

Role of the SLP

In many cases, the SLP is asked to operate in the role of case manager or team leader because communication is frequently cited as a primary area of concern and one that influences all other aspects of daily living and life skills. Whether serving in this role or not, the SLP must be able to integrate information from multiple sources and disciplines in order to assist in designing an appropriate AAC program for an individual.

The SLP must acknowledge the need for expertise from other service providers who may include, but certainly not be limited to, physician, occupational therapist, physical therapist, vision specialist, rehabilitative engineer, teacher, psychologist, behavior consultant, and social worker. No less significant is input from parents, spouses, employers, and significant others. AAC is viewed as a means by which clients can promote or maintain a desirable quality of life. Such a vision should be pervasive in all AAC activities, regardless of the area of specialization of any particular professional.

The SLP is expected to be able to recognize the limits of his/her expertise and issue referrals to appropriate colleagues as necessary. It is strongly recommended that the AAC team be driven by the client and his/her family to the greatest extent possible. Part of the AAC program should be dedicated to finding and implementing ways in which the client can have maximal input regarding the disposition of the program.

(Source: http://www.asha.org/policy/TR2004-00262/) 3/5/14

Individuals who are unable to effectively communicate (via speech, sign, gestures, low tech aids, etc.) with other than familiar communication partners may need an SGD to fully meet all of their communication needs. In comparison to other modes of communication, SGD features (e.g., intelligible voice output, access to extensive vocabulary, ability to pre-store utterances for later delivery at the normal speech rate, etc.) can enhance communication and participation, allowing children and adults with complex communication needs to communicate with more people about more topics for a wider array of purposes.

Maximizing the benefits of an SGD requires several steps and will involve people with many different specialties. As a starting point, the following steps should be discussed with the potential user and those supporting his/her communication abilities. These are only highlights of what should be considered, individual needs and situations will very much influence the answers to these steps. Each step is given more detail later in the paper.

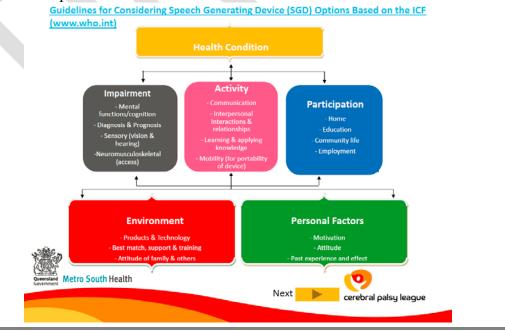
- Identification of needs and abilities
- Selection of systems to consider during the assessment period, along with peripherals if needed for access
- Assessment which requires support, and preliminary SGD system programming
- Collection and analysis of data during assessment
- Selection of final system, and backup
- Determination of potential funding sources
- Writing a request to eligible public or private funding sources for the SGD and needed services
- Establishing a written appeal if initial funding request is denied. (Refer to Appendix for possible funding sources and sample letters)
- Development of plan for system arrival

- Take delivery and inspection of system to ensure that it is in working order, and that peripherals and accessories are as ordered
- Initial programming, or transfer of vocabulary and settings from an earlier system
- Initial user training and training of relevant support persons
- Follow up training as needed for user and key support persons
- Refinement of vocabulary after a period of use to ensure appropriate vocabulary for each environment
- Educate user and support person(s) about maintenance, including charging, positioning, cleaning, troubleshooting, warranties, rentals, and backups
- Periodic evaluation and re-evaluation when growth, change of environments, or other situations occur

Depending on the individual and his/her needs and environments, the following people might be involved in the process:

	manujaciurer or representative
The Individual	Occupational therapists
Family	Physical therapists
Friend or Life partner	Rehabilitation Engineers
Caregivers and other support people	Rehabilitation Engineering Technologists
Speech Language Pathologist	Assistive Technology Professional
Educational staff	Nursing Staff
Residential staff	Social Workers
Day program staff	Physicians
Program manager	Vision Specialist
Distributors, (if not the manufacturer)	Vocational Rehabilitation Counselors

1)Identification of needs and abilities: A Speech Language Pathologist (SLP) should be consulted when a person has a speech impairment and is unable to meet daily communication needs using natural speech or other communication methods.



This consultation can be initiated by an individual, family member, Dr., educator or therapist.

For some individuals, following sufficient therapy and practice, oral speech will meet their communication needs. Others will require a temporary or permanent augmentative communication system as supplement to or substitute for oral speech. A question to ask is "Does the individual's natural speech enable him/her to communicate on an age appropriate level about a variety of topics, for a variety of purposes, with a variety of communication partners. If the answer is YES, the augmentative communication approach may not be needed. If the answer is NO, then it suggests the need to explore an augmentative communication system.

An augmentative communication system consists of all of the non-speech modes someone might use to communicate: vocalizations, gestures, body language, facial expressions, manual signs, low and high tech communication aids, etc. Amongst other responsibilities, the SLP is responsible for analyzing what modes are used in what situations, with what partners, to determine when additional modes, including an SGD, might better meet someone's communication needs.

Note: The focus of this guide is on Speech Generating Devices (SGDs), including specialized devices (often referred to as "dedicated devices") and mobile technologies with SGD Apps.

2) Selection of systems to consider: This should be led by the client and/or the client's family in collaboration with a Speech and Language Pathologist (SLP) who has training and experience with SGDs with contributions from other team members as needed. (Note, this should be a trans-disciplinary process in which those with the greatest expertise taking the lead in specific areas of concern in ways that meet clients' needs and does not compromise professional licenses. For instance, the SLP may not have the most experience in providing SGD services and should seek consultation from an SLP or other professionals experienced with these devices)

In many instances, it is beneficial for the client to use the actual equipment for a trial period. Devices for this trial may come from a lending library, colleague, other organization, or a manufacturer.

If alternative access is needed, an experienced Occupational Therapist (OT) and/or Assistive Technology Professional (ATP) may lead this part of the evaluation. Alternative access includes keyguards, hand splints, mouth or head pointing device, eye gaze, joystick, or switch use. The OTs role might also include consulting on positioning and transportation of equipment, access to electronic aids to daily living, and writing options.

If the client uses a wheelchair, the OT, PT, and/or ATP may be involved to mount equipment and switches, and to make modifications to the system. In addition, a seating evaluation may be needed to ensure that the individual is sitting in a stable and comfortable position and has optimal range of motion.

As determined through formal and informal assessment, when selecting an SGD and communication software, the following should be considered:

- client's current expressive and receptive language abilities
- communication goals and anticipated future communication needs
- cognition
- physical access
- mobility and positioning
- vision and hearing of the client
- variety of a client's communication environments

Literacy skills must be taken into account even when the trial device is selected. If the individual has solid literacy skills (spelling, word recognition and text comprehension), the range of symbol systems is quite varied. These symbols can be words, letters, and phrases and the voice output can be both synthesized and digitized. However, if literacy skills are limited, visual symbols (photographs, pictures, and visual icons), or tactile symbols (objects or textures) will be needed to represent desired words or concepts.

Hardware features to consider include: device size, screen size, weight, battery life, switch ports, speaker volume, equipment quality and durability, portability, access and connectivity options including WiFi, Bluetooth, a SIM card slot, and/or infrared.

Software features to consider include: the presence/absence of synthesized speech, accessibility options, scanning options, text-to-speech functionality, available symbol sets, presence/absence of supports for communication via text-based message generation, novel message generation using symbols or words, or whole-message-based communication; ability to interface with other software applications. There are several matrices that can help with the feature match. See, for example, the Feature Matching Matrix from Boston Children's Hospital.

Consideration should also be given for a backup system (either high, low, or no-tech). This is especially important for many SGDs, when the primary device is not available or would be inappropriate to use. This would include situations where it would be damaged if used, if it was out of power, or in need of repair. Backup systems may also be used by the care team to learn the language program.

For the trial period to be meaningful, a knowledgeable person must be available to set up the device, demonstrate the operational features of the device, and provide training and support as needed by either the individual and/or significant persons.

Collection and analysis of data during trials: Various data collection tools are available to collect data on communication intent, and use in various environments. Data collected during trials can be analyzed and summarized to determine the best fit.

3) Selection of final system, and backup: All individuals in regular contact with the potential SGD user should review the proposed solution and give feedback on any concerns. With feedback and data collected during trial, the final system can be determined and justified. Once again, a feature matching process should be used in selecting the final SGD device. This along

with the results from the trial system should form the basis for this final selection. All of this information should be included in the funding request letter discussed below.

Team considerations:

- 1) Is an extended warranty recommended?
- 2) Is a second charger needed, one for home, the second for day activities?
- 3) Would a protective case or carry strap be useful?
- 4) Do the device and peripherals need to be mounted on one or more wheelchairs or locations?
- 5) If a wheelchair is used, how will the device be accessed when not in the chair?

4) Writing Reports or letters to secure funding: The focus of the report generally depends on the funding source. For example, if Vocational Rehabilitation Services is approached for funding, information about how the device will allow the client to communicate at work should be included. If a public or private medical funding source is approached, information on how the client can better communicate with medical personnel should be included and how this system will aid in maintaining functioning of the person. If funding is being requested through education, reference should be made regarding how the use of the device and services will enable to the student to access a Free and Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE) as required by Individuals with Disabilities Education Act (IDEA).

Some funding sources require a separate letter, summarizing the evaluation. Some SLPs provide a cover letter with the funding request with information on where each piece of the system could be purchased. A video of the person using the SGD may help with some funding sources.

There are many resources available to help users, families and professionals develop effective letters of necessity. The search for these resources may begin with the manufacturer or distributor of the SGD.

SPEECH GENERATING DEVICE (SGD) FUNDING

Frequently Asked Questions (FAQs)

http://www.aacinstitute.org/Resources/Funding/040922SGDfundingFAQs.html These are the Medicare criteria for coverage of a SGD.

(Source: <u>http://www.aacinstitute.org/Resources/Funding/SGDFundingRequirements.html)</u> 3/21/14

5) Development and implementation of plan for system arrival and set up:

A plan should be established to determine where the equipment will be delivered, and who will be responsible for collecting the system components. Once delivered, inspection of the system must take place to verify that it is in working order, and that options and accessories are as ordered. This can be performed by several individuals including the SLP; originator of the SGD order and/or an ATP.

6) Initial programming or transfer of vocabulary and settings from an earlier device: Next, the SLP or team member most knowledgeable about the SGD, with input from user and careproviders, will set up and customize the device. The OT will set up access to the device, and the Rehabilitation Engineer (RE) or ATP will mount any accessories. Speech aides, family members and others may be trained to assist in this step. Once settings and vocabulary are initially programmed, if the device permits, it should be backed up to a computer or other device. The OT must ensure that proper access to the device is available. The RE or ATP will work with the OT and PT to mount equipment and accessories or to make seating or mounting adjustments.

Initial training of user and team: This should be provided by the SLP so the system can be used to increase communication as early as possible. There may be situations when someone other than the SLP provides the initial training; if the SLP is unfamiliar with SGDs or with the particular system. In that case, initial training can be provided by another trained professional, a representative from the SGD manufacturer or distributor, or a competent person who uses the SGD. As soon as possible, a local SLP should be consulted and/or trained so that ongoing user training and support can be provided, allowing the user to best operate their new voice.

For individuals with intact cognition and literacy skills, setting up the device may require as little as a single visit. For others, vocabulary selection, arrangement, and language/communication training may involve months or years of on-going intervention.

7) Follow up training of user and team: The vendor may be involved with teaching the team how to program and customize the SGD. The OT, PT, and ATP may be involved to teach the team to adjust mounts, and input systems. The OT and vendor may work with the teacher and other team members to determine how the system will be used to access writing or electronic aids to daily living. The SLP and/or "device knowledgeable" team member with a Train the Trainers approach could allow User, Teacher/Program Staff/Residential Staff and/or Caregivers to provide on-going support in "real time". Training should focus on operational competence, communication/strategic competence, and, where necessary, linguistic competence.

Please see:

Toward a Definition of Communicative Competence for Individuals Using Augmentative and Alternative Communication Systems by Janice Light

(Source <u>http://informahealthcare.com/doi/abs/10.1080/07434618912331275126</u>) 4/24/14

8) Refinement of vocabulary: This should be conducted after a period of use to ensure vocabulary usefulness and appropriateness for each environment. Include SGD User, Teacher/Program Staff/Residential Staff and/or Caregivers with support of an ATP if applicable. This stage of the process may again require ongoing SLP intervention, as the initial device vocabulary may be outgrown and the user needs access to additional vocabulary.

Please note: Depending on location, professional services MAY NOT be financially covered as on-going service delivery. If the client will be in an environment in which there will not be continued support by therapists or ATPs, it will be important for the team to train family or

support staff on how to upgrade language and settings. They should be provided with contact information to seek assistance.

9) Reevaluation of SGD access: After a period of use, the SGD access method and settings should be rechecked to determine if they are still optimal for the user. Some users may improve in abilities, others may decline. An OT or ATP may be beneficial at this step.

10) Daily care and long-term maintenance of system: The team should determine who will provide daily care, updates, and ongoing maintenance of the system and document this plan. Some teams have developed charts to track daily care, to schedule periodic update checks, and to document maintenance procedures. For example, an evening care staff may be assigned to charge a device, an ATP may be assigned to update the device software every six months. The contact information, warranty information, and process for sending a device for repair may be documented in the client records.

Questions that the team may ask during periodic maintenance checks are:

Do batteries, either non-rechargeable or rechargeable need to be replaced? Have parts fallen off or got damaged? Are the charger, cords and other accessories in good condition?

If an extended warranty was purchased, the system should be carefully checked before the warranty expires to see if repairs are needed.

11) Peripherals: Additional training and support may need to be provided to the individual and team on how to interface the SGD with other technologies, such as computers, printers, cell/smart phone, Bluetooth and WiFi, based on the ADLs of the user. This might be provided by an OT, RE or ATP.

12) Evaluation of device use and the effectiveness of training and support: This should be conducted based on user needs, funding requirements, state practice acts and regulations. Several outcomes measures should be included; expansion of the topics of communication, variety of communication partners, and measures of community/school/workplace participation.

(Source: <u>http://www.cms.gov/Regulations-and-</u> <u>Guidance/Guidance/Transmittals/downloads/r63bp.pdf</u>) 4/24/14

NOTES

- Most states have lending libraries of a variety of AT devices, including SGD. To identify your state program, go to ATAP—Association of Assistive Technology Programs at <u>http://www.ataporg.org/</u>
- 2) All of this may sound quite technical; however, the preference of the Person Who Uses AAC (PWUAAC) and his/her significant caregivers and other support people must also be given priority. Research on abandonment of AT includes the following factors:
 - a) The technology was not well matched to the individual's needs.
 - b) Little or no training and support was provided.
 - c) Families were not accepting of the technology.
 - d) School or workplace was not accepting of the technology.
- 3) Several resources are available via the web to assist you in writing funding requests including sample letters.
 - a) <u>http://www.augcominc.com/index.cfm/funding.htm</u>
 - b) http://aac-rerc.psu.edu/index.php/pages/show/id/5
 - c) <u>https://www.pinterest.com/vsucsd/aac-funding/</u>
- 4) Understanding the funding process:

http://www.tobii.com/Global/Assistive/Funding/Understanding%20funding/understa nding-funding-slps-new.pdf?epslanguage=en

5) Sample letters for AAC funding:

http://www.aacfundinghelp.com/ http://aac-rerc.psu.edu/index.php/pages/show/id/21 http://www.prentrom.com/funding/advocacy-and-appeals

GLOSSARY

AAC	Alternate Access Communication
ADL	Activities of Daily Living
ALS	Amyotrophic lateral sclerosis (Lou Gehrig's Disease)
ATP	Assistive Technology Provider (certificate provided by RESNA)
CMS	Centers for Medicare and Medicaid Services
DME	Durable Medical Equipment
EADL	Electronic Aids for Daily Living
FAPE	Free and Appropriate Public Education
IDEA	Individuals with Disabilities Education Act
LRE	Least Restrictive Environment
OT	Occupational Therapist
PT	Physical Therapist
PWUAAC	People Who Use Alternative Access Communication
RE	Rehabilitation Engineer
SGD	Speech Generating Device
SLP	Speech Language Pathologist
VOCA	Voice Output Communication Aid