Upfront

This issue seeks to expand the boundaries of our thinking about the rights of people with complex communication needs (CCN). Examples of more equitable or comprehensive thinking about these rights are already being put into motion around the globe. In preparing this issue, I worked extensively with Barbara Collier from Canada. Hilary Johnson and her colleagues from Australia, Inger Larsson from Sweden, Eija Roisko from Finland and Johana Schwartz from the United States also contributed enormously. The ideas and passion of my colleagues permeate each article.

During the *ISAAC Biennial Conference* in Montreal (August 2008), the buzz about "access" in AAC extended well beyond past discussions about access to speech generating devices (SGDs) and mainstream technologies, using eye gaze systems, infrared pointers, scanning and so on. AAC devices and materials were, of course, prominently displayed in the exhibit hall and were of continuing interest.

The real excitement at *ISAAC 2008*, however, was powerfully demonstrated by the 100 plus children and adults who rely on AAC in attendance. These individuals gave sessions, received awards, participated actively in all activities and expressed their ideas clearly and often. To them,

access means participating equally, belonging, engaging in preferred activities, building social networks, hanging out with friends, and so on. In short, *access* for people who rely on AAC means realizing one's human and civil rights.

Without a way to communicate, people with CCN are denied access to almost everything. But, having and using AAC technologies, even sophisticated ones, is far from enough. To participate and enjoy equal access to society, people

Clinical News

Communication access for people who rely on AAC

The disability rights movement aims to improve the quality of life of people with disabilities. Years ago, the medical model of disability focused society's attention on an individual's "impairments." This resulted in society treating people with disabilities as "objects" to be managed, rather than "subjects" bearing equal rights and deserving the full protection of the rule of law.[2]

Emerging from the civil and human rights movements of the 1960s, today's social model of disability is reflected in national and international laws, treaties and policies.[3,4,5] The social model shifts our understanding of "disability" away from the

false dichotomy of being either "able-bodied" or "disabled," toward a recognition that societal barriers, prejudices and exclusions (purposely or inadvertently) largely define who ultimately is, and who is not, excluded from a particular community, neighborhood, school, *etc*. The social model recognizes that people with disabilities do not need to be "fixed" or "cured." Rather, our communities need to more freely, openly and without pity accommodate ALL persons.[6]

Equal access for people who rely on AAC

Gaining access to city streets, public bathrooms, elevators and buildings does not begin to address the myriad of barriers people with complex communication needs (CCN) confront. To date, however, accessibility guidelines and resourc-

es in most countries focus on the needs of people with limited mobility (*e.g.,* building codes that define physical access in new and existing buildings) and people who are deaf, hard of hearing, blind, visually impaired or deaf-blind (*e.g.*, alternate format requirements, captioning, sign language interpreters, intervenors, *etc.*)

The communication access needs of people with limited or no speech and those who have difficulty understanding spoken/written language are largely ignored. In fact, most communication access policies and regulations do not even mention people who rely on AAC. [A recent exception is the *UN Convention on the Rights of People with Disabilities*. See article on page 4.] The AAC community has been far too complacent.

Communication access

Communication access is a key that unlocks the doors to society. The disability community defines accessibility broadly, acknowledging that barriers exist to communication, information, transportation, housing, education, employment, the Internet, mainstream technologies, adaptive technologies, the legal system, the continuum of healthcare, and other community services (police, retail, entertainment, leisure, places of worship). No longer does 'access' just mean getting out, hearing words spoken or seeing posted information. Access today means having ways to participate actively and equally alongside others in the community. This requires an ability to communicate in authentic and meaningful ways.

Communication curb cuts

AAC strategies and technologies are curb cuts to communication for people with CCN. Curb cuts are those concrete ramps between the street and sidewalk designed to provide physical access for people in wheelchairs to their communities.

with CCN require public laws and policies that consider their needs. In most places, few or none exist, even though the needs of other groups with communication disabilities are considered or even mandated. People who are deaf/hearing impaired, blind/visually impaired and deaf-blind have specific rights to communication technologies and supportive services (*e.g.*, sign language interpreters, intervenors, Braillers, *etc.*). These services are funded (albeit too often underfunded), implemented, regulated and accepted in most communities.

This issue argues for the need for the AAC community to demand equal rights for individuals who rely on AAC. **Clinical News** features a discussion on communication access issues. The **Governmental** section highlights the relevance of the United Nations *Convention on the Rights of People with Disabilities* to the AAC community. **For Consumers** argues for provision of professional *communication assistant* services and the **AAC-RERC section** illustrates an example of such services. According to Sudha Kaul, ISAAC president, "Communication access is a human rights issues and the AAC community has work to do."[1] I agree. Let's go do it! ➲

Sarah W. Blackstone, Ph.D. CCC-SP

Lots of people, including those with no physical limitations, use curb cuts as well as grab bars, ramps and automatic door openers. In addition, virtual curb cuts designed for people with physical limitations help many others access information on the Internet. Increasingly in our global economy, communication curb cuts are needed by people who speak different languages. For example, first responders and emergency personnel use pictures and graphic symbols on communication displays to provide information or ask people questions in stressful situations. Symbols also point the way to restrooms, hospitals and other public facilities.

Existing laws and policies have made most communities aware of the need for sign language interpreters, Braille in elevators, signals at intersections and readers in our schools. These communication curb cuts are accepted accommodations. Importantly, they include both human supports and assistive technologies. The problem for people who rely on AAC strategies and technologies is that few communication curb cuts are mandated for them. Rather, they are ignored in laws and public policies, or if included, programs are underfunded and/or unregulated. The resulting disenfranchisement of children and adults whose speech is difficult to understand and/or who have difficulty understanding spoken language for reasons that extend beyond their hearing and visual capacities is unacceptable.

Solving communication access issues

To improve communication access, the AAC community needs to ensure that individuals with CCN can **access the communication supports they need to realize their rights**. This includes AAC technologies and strategies, as well as trained, professional communication assistants. [For an in-depth discussion of communication assistants, go to **For Consumers**, page 8 and **AAC-RERC**, page 13.] In addition, the AAC community must **work on legislation and public policy** to ensure that people with limited or no speech and those who have difficulty understanding spoken and/or written language can access the supports they need to participate fully in their family, neighborhood, community and society. [See **Governmental**, page 4.] Finally, we need to **build community capacity** so people who rely on AAC are welcomed participants who enjoy equal rights.

Communication Bill of Rights

In 1992, the National Joint Committee for the Communication Needs of Persons with Severe Disabilities, a group comprised of representatives from the American Speech-Language-Hearing Association and six other organizations in the United States put forth a *Communication Bill of Rights*.[7] It states that all people, regardless of the extent or severity of their disabilities, have a basic right to "affect, through communication, the conditions of their existence," and that "each person has specific rights during daily interactions to:

• refuse undesired objects, action, or events

• express personal preferences and feelings

• be offered choices and alternatives
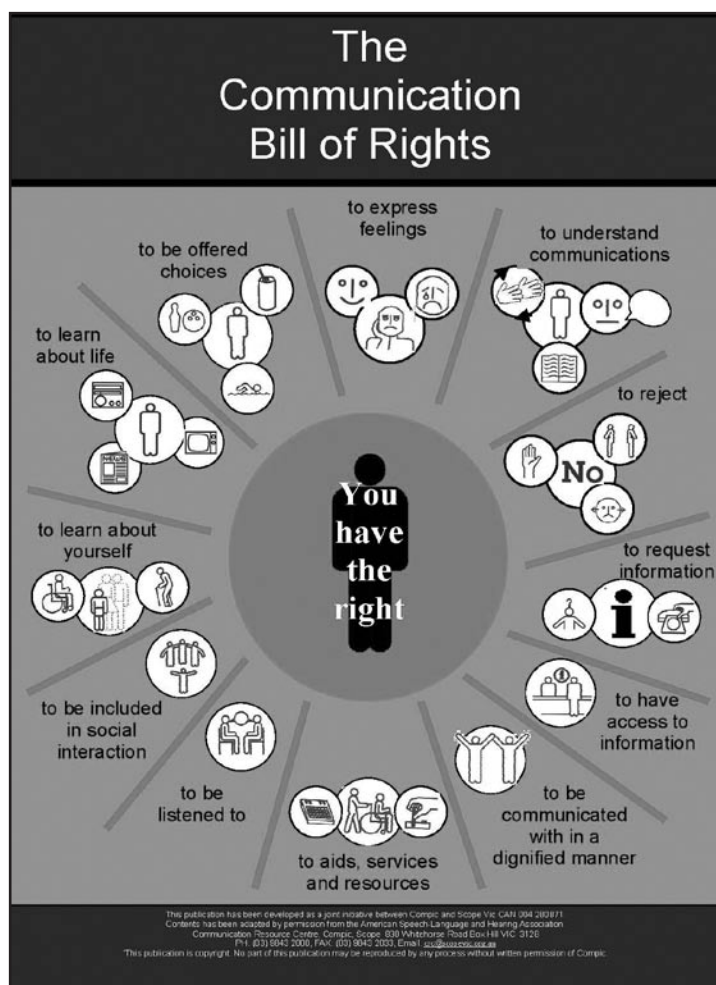
The *Communication Bill of Rights* poster was developed as a joint initiative between Compic and Scope Victoria in Australia.[8] It illustrates the National Joint Committee for the Communication Needs of Persons with Severe Disabilities' *Communication Bill of Rights.*[7]

Poster contents were adapted with permission from the American Speech- Language and Hearing Association.

For a free download, go to www.scopevic.org.au/therapy_crc_r&p.html

• reject offered choices

• request and receive another person's attention and interaction

• ask for and receive information about changes in routine and environment

• receive intervention to improve communication skills

• receive a response to any communication, whether or not the responder can fulfill the request

• have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times

• have AAC and other AT devices that function properly at all times

• be in environments that promote one's communication as a full partner with other people, including peers

• be spoken to with respect and courtesy

• be spoken to directly and not be

spoken for or talked about in the third person while present

• have clear, meaningful and culturally and linguistically appropriate communications."[7]

Community capacity building

Recognizing that people who rely on AAC face significant barriers to inclusion in their communities, the Communication Resource Centre, a service of Scope* and 11 regional communication services decided to launch a community capacity building project in 2004.[9] Speech-language pathologists, occupational therapists and individuals who rely

* Scope is a not-for-profit organization providing disability services throughout Victoria to thousands of children and adults with physical and multiple disabilities.

on AAC decided to provide shop-keepers and office managers with communication displays for their businesses and to distribute generic communication boards and brochures. These activities were centered around Centro Box Hill shopping center in Melbourne.[10]

The project, now known as *Good Communication is Good Business,* is spreading fast. A brochure (*Figure 1*) with pictures emphasizing good customer service and a communication accessible sticker (*Figure 2*) were developed. The four-page brochure (available in English, Vietnamese and Mandarin-Chinese) helps raise employee and customer awareness and is useful in training new employees. The sticker can be prominently displayed in stores and offices.
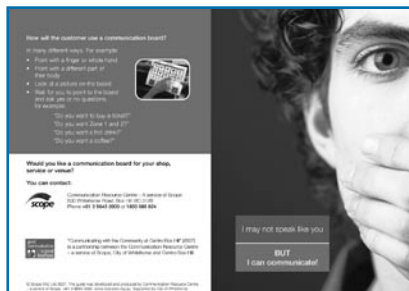

Figure 1. Cover and last page of four-page brochure.

Figure 2. *Good Communication is Good Business* sticker.

Participating business managers report results that include a positive change in attitude and increased awareness of how to communicate with people who have communication difficulties. The *Good Communication is Good Business* project will soon extend to three additional regions. In the meantime, changes are underway to the brochure and communication accessible symbol.[10]

For more information on the project, go to www.scopevic.org.au/news_crc_centro.html or contact Barbara Solarsh at bsolarsh.crc@scopevic.org.au

Summary

Without the right to communication access, there is no equality for people with CCN and too few are included in their communities. Sadly, people with CCN, even those who use AAC, are still denied equal access and equal rights. It is essential that legislation and public policies specifically address their rights.

Distributing brochures with information about communication access in Melbourne. A communication display hangs from the counter in the shop.

While crucial, having access to AAC technologies is not enough! People who rely on AAC need to be *at the table* when policies affecting their lives are negotiated. Without advocacy, communication access will continue to be defined in ways that exclude, rather than include, people with CCN who rely on AAC.

Governmental

The *UN Convention on the Rights of Persons with Disabilities* with Barbara Collier

Finally, an international treaty sets legally binding obligations to ensure the rights of all people with disabilities in all areas of their lives and doesn't leave people who rely on AAC out of the equation.[11] The *United Nations Convention on the Rights of Persons with Disabilities* was negotiated during eight sessions of an *ad hoc* committee of the General Assembly of the United Nations from 2002 to 2006 and adopted by the General Assembly in December 2006.[12] The *Convention* and its *Optional Protocol*

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[i] An *Optional Protocol* is a legal instrument to address issues not covered, or not sufficiently covered, in a parent treaty. States party to the *Convention* are not obliged to sign the *Protocol* but may if they choose. The *Optional Protocol to the Convention on the Rights of Persons with Disabilities* introduces two procedures:
(1) Individual communications. A mechanism that permits individuals and groups of individuals to complain to the Committee on the Rights of Persons with Disabilities if a State has breached one of its obligations under the *Convention*.
(2) Inquiry. A mechanism that permits the Committee to address systematic and widespread violations of the rights of persons with disabilities, make recommendations and work with States to remove impediments.

To read the *Optional Protocol,* go to www.un.org/disabilities/documents/convention/convoptprot-e.pdf Pages 31 - 37.

was proclaimed an *entry into force*[ii] at the United Nations in May 2008, becoming one of the fastest treaties ever negotiated. Today, the *Convention* has 130 *signatories*.[iii] Notably, the United States, Russia and some countries in Africa, the Middle East and Eastern Europe have not yet signed on. The National Council on Disability in the United States has published an analysis of the *Convention* and recommended signing the document and has identified areas in which U.S. laws and policies would need to change.[13]

The stated purpose of the *Convention* is to:

> Promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.[14]

While clearly a human rights instrument, the *Convention* has an explicit social development dimension and underscores a "paradigm shift" in attitudes and approaches to a social model of disability that is already reflected in existing laws and policies of many nations.[15] A press release about the *Convention* states:

> It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.[16]

What's in the document?

The *Convention on the Rights of Persons with Disabilities* includes a preamble and 50 articles. It identifies areas where adaptations can effectively enable people with disabilities to exercise their rights. It also

highlights spheres in which rights have been violated (physical and emotional abuse, crime, discrimination) and specifies ways to reinforce protection of those rights.

"States" (countries) and "regional integration regions" (*e.g.*, the European Union) who sign, ratify, or *formally confirm*[iv] the *Convention* agree to take appropriate measures to ensure the implementation of all articles. Table 1 on page 6 provides a list of the 50 articles.[17] The first 30 articles relate to the rights of persons with disabilities. All are relevant to the AAC community. Others specify implementation issues and processes for *Convention* signatories.

While the AAC community should become familiar with all aspects of the *Convention,* the articles highlighted below are of key importance. Each validates the need for legislation and policies that support the use of AAC strategies, techniques and technologies.

Article 2 (Definitions) explains five terms: C*ommunication, language, discrimination on the basis of disability, reasonable accommodation* and *universal design*. For example, the definition of communication states:

> Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and *augmentative and alternative modes, means and formats of communication, including accessible information and communication technology*.[18] [italics added.]

<u>Importance.</u> The UN's definition of communication further validates AAC as a mainstream approach to overcoming com-

munication barriers, putting AAC modes, means and other formats of communication on an equal legal status with Braille, sign languages, writing and speech.[18]

Article 4 (Obligations) lists policies, laws and administrative measures that States and regional integration organizations need to enact to secure rights recognized in the *Convention.* It also specifies measures that abolish laws, regulations, customs and practices that constitute discrimination. Further, Article 4 affirms that no discrimination of any kind should be made on the basis of type of disability.[19]

<u>Importance.</u> The list of obligations in Article 4 highlights several issues pertinent to the AAC community. For example, it recognizes the need for persons with disabilities to access communication technologies, as well as for States to promote the availability and use of new technologies at affordable costs. In addition, it emphasizes the obligation of States to recognize the need for human supports to ensure the rights of people with disabilities (*e.g.*, sign language interpreters, communication assistants, speech interpreters and readers).

Article 4 also states that professionals and staff who work with persons with disabilities need to

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ii **Entry into Force** refers to the process by which a treaty comes to have legal force and effect.

111 To see a map of participating countries and their status regarding the *Convention* and the *Optional Protocol, g*o to www.un.org/disabilities/documents/maps/enablemap.jpg

iv Each of these is slightly different. States and international regions (*e.g*., the EU) have options. Go to www.un.org/disabilities/default.asp?id=231 for a complete description of differences. Basically, signing the *Convention* is not legally binding, all others options are.

Table I. Articles of the *Convention on the Rights of People with Disabilities*			
1 Purpose	11 Situations of risk and humanitarian emergencies	21 Freedom of expression and opinion, and access to information	**Articles related to Process** 31 Statistics and data collection
2 Definitions	12 Equal recognition before the law	22 Respect for privacy	32 International cooperation
3 General principles	13 Access to justice	23 Respect for home and the family	33 National implementation and monitoring
4 General obligations	14 Liberty and security of person	24 Education	34 Committee on the Rights of Persons with Disabilities
5 Equality and non-discrimination	15 Freedom from torture or cruel, inhuman or degrading treatment or punishment	25 Health	35 Reports by States Parties 36 Consideration of reports
6 Women with disabilities	16 Freedom from exploitation, violence and abuse	26 Habilitation and rehabilitation	37 Cooperation between States Parties and the Committee
7 Children with disabilities	17 Protecting the integrity of the person	27 Work and employment	38 Relationship of the Committee with other bodies 39 Report of the Committee
8 Awareness raising	18 Liberty of movement and nationality	28 Adequate standard of living and social protection	40 Conference on State Parties 41-43 Depository, Signature, Consent to be bound
9 Accessibility	19 Living independently and being included in the community	29 Participation in political and public life	44 Regional integration organizations 45-47 Entry into force, Reservations, Amendments
10 Right to life	20 Personal mobility	30 Participation in cultural life, recreation, leisure and sport	48-50 Denunciations, Accessible format, Authentic texts

Governmental, Continued from page 5

participate in trainings, so they can provide the assistance and services guaranteed by the *Convention*.[19]

Article 9 (Accessibility) addresses communication access, as well as "access to the physical environment, transportation, information and other facilities and services open or provided to the public in urban and rural areas." For example, Article 9 specifies the need for States to provide public signage in Braille and in other forms that are easy to read and understand. Also, it acknowledges that some people with disabilities require "live assistance and intermediaries, including guides, readers and professional sign language interpreters to ensure access to information, buildings and other facilities open to the public."[20]

Article 9 requires countries to identify and eliminate existing obstacles and barriers and to take steps to ensure that people with disabilities gain access to their communities.

Importance. Article 9 defines access broadly and extends accessibility issues well beyond physical access and access to information. It specifies communication access and access to other services (such as electronic services, emergency services and the Internet) as rights. It recognizes, but does not specify, that providing communication access to persons with limited or no speech is needed for them to participate equally in society, and that they, too, require a full range of accommodations (*e.g.*, AAC technologies, strategies and techniques, as well as human supports).[20]

Article 21 (Freedom of expression and opinion, and access to information) affirms that people with disabilities should have the "freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice."[21]

Importance. This article refers back to the definition of communication in Article 2, which includes AAC modes, means and formats of communication, as well as making information and communication technologies accesssible.[18]

Article 21 specifies that signatories promote access to information, as well as freedom of expression and opinion by:

(1) providing information intended for the general public in accessible formats and technologies.

(2) facilitating the use of Braille, sign language and other forms of communication (*e.g.*, AAC modes, means and formats).

(3) encouraging media and Internet providers to make online information available in accessible formats.[21]

Importantly, Article 21 states that alternative methods are legitimate ways to communicate during official interactions and extends the right to communicate not only to people with sensory impairments (*i.e.*, persons with disabilities affecting hearing and vision), but also to other disability groups (*e.g.*, people who have limited or no speech, people with cognitive/linguistic/intellectual disabilities). Finally, Article 21 affirms the rights of people with disabilities to use "all forms of communication of their choice."[21]

Article 24 (Education) recognizes the right of persons with dis-

abilities to an education and requires signatories to "ensure access to an inclusive, quality and free primary and secondary education on an equal basis with others in communities where individuals with disabilities live."[22] States are to make necessary accommodations to "maximize academic and social development, consistent with the goal of full inclusion."[22] Among the accommodations specified are:

a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, as well as facilitating peer support and mentoring.

b) Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf/blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

c) Employing teachers, including teachers with disabilities, who are qualified in sign language and/or Braille.

d) Training professionals and staff who work at all levels of education in ways that incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.[22]

Importance. Article 24 validates the need for AAC modes, means and formats of communication and states that signatories need to provide equal access to primary and secondary education. It explicitly specifies that students who require supports get what they need, and that students who are blind, deaf and deaf-blind receive their education in the most appropriate modes of communication from teachers who are fluent in sign language and Braille.

Article 24 reverberates for students who rely on AAC. They,

NOTHING ABOUT US WITHOUT US

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
KONVENTA MBI TË DREJTAT E PERSONAVE ME AFTËSI TË KUFIZUARA
KONVENCIJA O PRAVIMA OSOBA SA OGRANIČENJIMA

too, need teachers who are fluent with AAC modes, means and the forms of communication they use. They, too, require teachers to use appropriate materials to maximize their academic and social development.

Finally, Article 24 affirms that the aims for education of persons with disabilities are to foster their participation in society, their sense of dignity and self-worth as well as the development of their personalities, abilities and creativity.[22]

For Consumers

Communication assistants: Human supports for communication access
with Barbara Collier

Individuals who rely on AAC have a right to support from people trained to help them communicate more fully in everyday situations. These services already exist for people with sensory disabilities. Individuals who are deaf can call on professional sign-language interpreters. People who are deaf-blind can use intervenor services. The blind can

Summary

The *Convention on the Rights of People with Disabilities* is a valuable source of rhetoric, vocabulary and political ammunition for use in advocacy, policy making, court cases, justifying public expenditures and professional education. People who rely on AAC, their advocates and everyone who works as an AAC professional must become familiar with this convention. It validates AAC as essential to the rights of people with disabilities who have limited or no speech and/or who have difficulty understanding spoken and written language.

The *Convention* builds on related human rights treaties,[23] but differs in that it sets out, with great clarity, legally binding obligations on all countries to promote, protect and ensure the rights of ALL persons with disabilities. It specifies the steps each must take so that persons with disabilities can enjoy true equality in society.

make use of professional readers. These professional services, while too often underfunded, give access to personal, social, educational and employment opportunities. Why aren't professional communication assistants* available to people who rely on AAC?

It's not because the need doesn't exist. Many people who rely on AAC ask family members, friends, classmates, teachers and/or caregivers to help them communicate in their communities or talk over the

* We use the term 'communication assistant.' Others use terms such as 'professional interpreter,' 'translator' or 'communication support worker.' Meanings vary. However, in all cases, the person who relies on AAC directs the assistant.

phone. Regretfully, there is still no recognition that people with complex communication needs (CCN) due to motor, cognitive or linguistic limitations need trained professional communication support services, similar to those available to individuals with sensory impairments.

The lack of professional communication assistant means people who rely on AAC have to make do with communication assistance from family, friends and other volunteers who may not be well-trained as communication assistants. No code of ethics, standards of practice or accountability protect people who rely on AAC from risk. Individuals have no recourse if a volunteer communication assistant breaches their privacy, accuracy or authenticity or misinterprets, misrepresents, or ignores their wishes.

This article explores the topic of professional communication assistants for people who use AAC. It gives three real examples and a plethora of useful materials with which to begin advocating for similar programs.

Terminology

The role of the communication assistant is different from that of a communication partner or communication facilitator. These differences are summarized below and in Table II.

1. Communication assistants support individuals with complex communication needs (CCN) to communicate with another person or persons, face-to-face, over the telephone or in writing. Professional communication assistants take direction from the individual who relies on AAC. They remain "outside" of the interaction.[24]

Individuals with CCN seek communication assistance from familiar partners in some situations. Few have access to professional communication assistants.

The roles and responsibilities of a communication assistant are not widely defined, recognized, understood, delineated or regulated. This is in sharp contrast to services for people with sensory impairments, where there are precedents regarding training, a code of ethics, job descriptions, standards of practice and accountability.

2. Communication partners represent the universe of interactants who directly (or virtually) converse, exchange information, share opinions, feelings, *etc*. Communication partners include family members, friends, acquaintances, paid workers, and complete strangers.[25]

When communication exchanges occur asynchronously using standard text (*e.g*., email, text messages), neither interactant has to make an adjustment. However, during face-to-face interactions and phone conversations, which occur in real time, conversational patterns become atypical and can be difficult. People who rely on AAC are often significantly disadvantaged. Specifically, natural speakers tend to (a)

dominate interactions, (b) ask predominantly yes/no questions, (c) take a majority of conversational turns, (d) provide few opportunities for augmented communicators to respond, (e) interrupt often, (f) focus on the user's technology or technique rather than the person or message and (g) fail to confirm the content of messages.[26]

For decades, many AAC programs and practitioners have recognized the need for communication partner training and tried to provide it. For example, primary communication partners may be taught how to use strategies that support interactions, such as how to respond to communication initiations, ask open-ended questions, use *yes*/*no* questions, co-construct messages, support the person when he/she does not

Examples of communication assistants working with people who rely on AAC

• John's sister, Maya, helps him make appointments by placing telephone calls. His speech is not always intelligible so John also uses a low-tech display to communicate. He signals Maya when to interpret his speech or speak aloud what he is pointing to. To begin the call, Maya says, "I am John's communication assistant. I am here to assist with communication."

• Lois's friend, Sarah, acts as her communication assistant when they go to church or attend meetings. Lois uses an alphabet board and speech generating device (SGD). During initial introductions, Lois says, "This is Sarah. She is here to assist me with communicating."

• Tom will accompany his wife, Mary, to the dentist. They realize they have limited time in the office. Mary have prepared some questions that she programmed in her SGD. During her appointment, she tells the dentist, "My husband is my communication assistant today. He will help you understand my communication."

• Joe has a neighbor that he sees frequently. He would like to engage in conversation with her but she does not know how he uses his communication board. Joe asks his assistant to explain how he communicates. "I am Joe's communication assistant. Joe has asked me to explain how he communicates."

Table II. Communication partners, facilitators and communication assistants		
Roles	Description	Who
Communication assistants	Provide communication support during interactions, as directed by the person who relies on AAC. Assistants do not participate directly in the interaction or instruct either communication partner.	Self-taught family members, personal or instructional assistants. Most people have to rely on volunteers because professional communication assistants are hard to find.
Communication partners	Directly (or virtually) engage in conversations with each other, exchanging information, feelings, *etc*. Can be face-to-face, written, telephone, e-mail, *etc*.	All potential interactants: family members, friends, acquaintances, paid workers/professionals and unfamiliar partners.
Communication facilitators [Not *facilitated communication* or other approaches in which authorship is questionable.]	Provide assistance/instruction to interactants. Depending upon the skills/abilities of the individual with CCN and the contexts wherein communication occurs, the degree of facilitator support can vary.	Typically, teachers, speech-language pathologists and family members who are trained in how to facilitate interaction using AAC technologies, strategies and techniques.

have needed vocabulary and so on. In reality, of course, most communication partners are not trained and never will be. Any guidance typically will come from the individual who uses AAC.

Communication facilitators are people who are trained to teach and coach individuals who rely on AAC. The facilitator's role is to ensure effective communication by demonstrating, modeling and/or instructing the person using AAC and/or the communication partner. Facilitators may prompt a person using AAC to take a communicative turn or support the person by rehearsing and modeling a communicative function. They may show a communication partner how to respond, pose a question in another way, provide more time for message construction or support message comprehension. They may also prepare new vocabulary for AAC technology, program a device or reposition the individual.[27]

The level of instruction and support communication facilitators provide often depends upon the extent to which the individual can communicate independently. Some individuals (*i.e*., very young children and those with significant cognitive/linguistic delays or disabilities) require maximal support across all contexts. Thus, facilitators may take on advocacy roles in some situations, *e.g*., negotiate appointments, meet with speech-language pathologists or seating specialists, *etc*.

AAC specialists, family members and other caregivers often function as communication partners, facilitators and communication assistants. These roles often overlap within a single day (or interaction). As a result, boundaries can (and do) get murky and crossed, even though each role is important and unique.

The need for professional communication assistants is being acknowledged. In Finland, for example, professional interpreter services are now legislated and available to people who rely on AAC. In Sweden, professional services are recognized in some municipalities. For the most part, however, communication assistants are volunteers and not mandated by government policy or laws. There is a growing

Table III. Speech Interpreter Service Curriculum in Finland	
General information	Laws, safety, ethics, continuing education, Interpreter services model.
Translation	Information about communication disorders, diagnostic categories. How to translate Bliss, unclear speech, typed messages into standard text, typed messages into speech. How to act when translating.
Interpretation	Communication methods to support interaction (*e.g*., pictures, graphics, drawing, signs, body language, expressions, gestures, writing, objects). Environmental considerations, attitudes, skills. Skills at interpreting content, confirming accuracy, explaining role of interpreter to a third party.
Communication supports	Use of communication tools, boards, speech generating devices.
Technical supports	Computer-based communication
Entrepreneurship	How to sell your services to the municipalities

recognition that people with CCN need these services and an increasing number of individuals and programs are working to provide them.[28]

Communication assistant services

Colleagues from Finland, Canada and Sweden shared information about communication assistant services for people who rely on AAC.

FINLAND: Interpreter services model.[29,30] Finland is the first country to recognize that all people with disabilities affecting communication, not just those with sensory impairments, are entitled to technologies and human supports. In 1994, the *Act on Services and Assistance for the Disabled* mandated that people who have difficulty "speaking or understanding speech, either spoken or written" could access Speech Interpreter Services (SIS) at no cost.

Speech interpreters enable people with speech impairments to take part in the everyday life of their communities, increase their autonomy and their capacity to live an equal life in society. Individuals who qualify are entitled to at least 180 hours of SIS services per year. Students have unlimited hours.

Speech interpreters assist people at work and in school and also provide the communication support needed to run errands, shop, conduct business in banks and service offices and to participate in social events, hobbies, clubs, seminars, meetings and leisure time activities. Speech
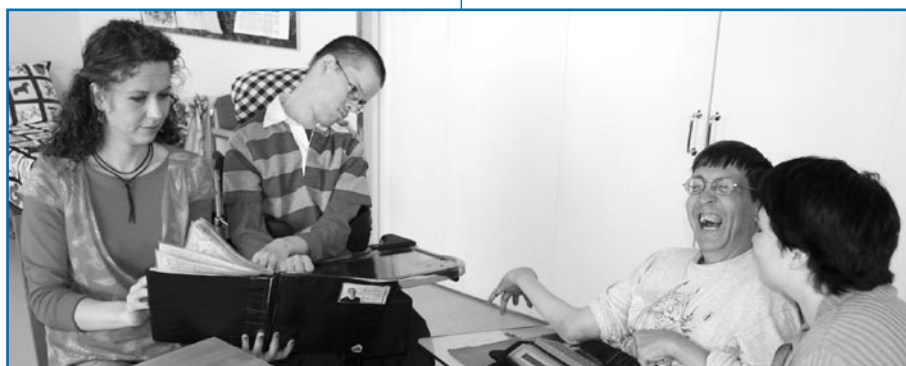
Speech Interpreter Services in Finland support the use of various communication modes

interpreters are trained to provide a wide variety of services:[31]

Translation. Translating from Bliss symbols to spoken or standard written language; clarifying difficult-to-understand speech; reading aloud as someone spells using an alphabet board.

Interpretation. Editing, collecting or expanding messages produced by a client.

Communication assistance and support/technical support. Taking care of communication aids, strengthening communication initiatives and advocating for individuals in the community.

SIS Training. SIS interpreters have to get a "specialist qualification" in a training program that lasts from 12-18 months and is offered at 11 community colleges. SIS interpreters learn a code of ethics and are required to demonstrate competencies in five of the six skill areas shown in Table III on page 9.[30] Through their classroom and practical experiences, interpreters learn about laws and ethical issues surrounding SIS, disabilities causing communication difficulties, AAC techniques, strategies and technologies, mainstream technologies and entrepreneurship. In 2007 there were 150 qualified SIS interpreters and more than 200 people with CCN who were using the services.[29]

Next steps. According to Eija Roisko, Director of the Communication and Technology Centre Tikoteekk in Helsinki, not all people who qualify for SIS services can access them. Reasons include a lack of information about their availability, as well as difficulty within municipalities in organizing and supporting SIS interpreters. In 2007, the Ministry of Finnish Social Affairs and Health began working with municipalities in Finland to investigate remote nationwide services to supplement existing SIS services and increase access.[29]

For more information, contact Eija Roisko at eija.roisko@kvl.fi

CANADA: The ACCPC Project.[28] In 2006, Barbara Collier and the Augmentative Communication Community Partnerships-Canada (ACCPC) hosted an informal focus

Tony Diamanti of ACCPC uses a communication assistant to speak his vows to his partner at a commitment ceremony

group for adults who rely on AAC, to discuss issues related to communication assistant services. Focus group participants strongly supported the need for communication assistant services. Subsequently, Canada's Social Development Partnerships Program funded the 12-month ACCPC's *Communication Assistant* project. The goal was to explore the use of communication assistant support for adults with congenital disabilities who rely on AAC.

Participants. Nine people who use AAC participated. Their ages ranged from 19 to 70 years. All have cerebral palsy, multiple disabilities and use power wheelchairs. All require assistance to accomplish daily routines, such as dressing, eating, drinking, *etc*. Three use alphabet boards and can access unlimited messages. Three rely primarily on their speech, using AAC displays to clarify messages. Three have limited vocabulary access (300 or more items) and limited spelling ability. Of the nine participants, six use direct selection and three rely on partner-assisted scanning to access their vocabularies.

Communication assistants. Project staff recruited 13 communication assistants. None were currently part of any participant's support team or social network. Participants wanted

communication assistants who would give them more privacy and independence. Project staff wanted to build a roster of communication assistant supports for future use. The majority of the communication assistants were university students or personal attendants. All had some work or volunteer experience with people with disabilities. None had prior training in communicating with people who rely on AAC.

Roles and responsibilities. Project staff and participants defined communication assistants as follows:

Individuals directed by persons who have communication disabilities to assist them in communicating with another person in face-to-face, written or telephone contexts.[24]

During the project, a set of principles emerged that addressed issues of authorship, accuracy, opportunities, authenticity and

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Principles for communication assistants[28]

1. Communication assistants will ensure and demonstrate the individual's authorship of all messages to their communication partners.

2. Communication assistants will strive to relay all messages with accuracy and fidelity and without addition, distortion, omission or embellishment.

3. Communication assistants will encourage third parties to engage in direct communication with the individual when directed to do this by the individual.

4. Communication assistants will ensure individuals they are supporting have opportunities to interject, contribute to and participate actively during all their interactions.

Developed by ACCPC (2008).
Go to www.accpc.com

completeness of intended messages to another person.

Communication assistant training. All communication assistants completed 30 hours in the classroom, a practicum of 20-30 hours with one-on-one coaching and attended several discussion forums.[28]

Best Practices for interacting with people who rely on AAC. Topics included multimodal communication, ways to find out what AAC techniques a person uses, ways to recognize and provide opportunities to communicate, how to pace an interaction, how to construct messages for people with reduced vocabularies and how to use questions in a conversation.

Code of ethics and standards of practice. The code of ethics covered issues related to confidentiality, impartiality, respect for all interactants, role boundaries, accountability, professionalism and privacy. Standards of practice focused on strategies to support people in communicating in face-to-face, telephone or writing with a third party.

Customizing communication strategies and discussing issues. These sessions involved customizing strategies and individualized coaching with participants.

Participant Training. The participants attended 30 hours of group educational sessions over nine months and five to twenty hours of individual support sessions to learn how to use communication assistant services and how to direct, evaluate and give feedback to communication assistants. They also met as a group and gave each other support and advice.

Services. The ACCPC established a centralized scheduling system so participants could book an assistant for a specific time. Assistants worked only as requested by the participants, so their work was part-time and *ad hoc*. Each participant was allotted a total of 14 hours of paid communication assistant support per month.

Frequency of use. All par-

Table IV. Service Agreement Between Consumers and Communication Assistants, by Barbara Collier, ACCPC, 2007-08
I, (**communication assistant name**), agree to provide communication assistance as directed by you and to abide by the following ethics:
• I will interpret your communication as accurately and faithfully as possible and to the best of my ability without adding, distorting, omitting or embellishing your messages.
• I will treat as confidential all information about you, that is either communicated or written and will not divulge this information without your consent.
• I will maintain impartiality by showing no preference or bias to you, any person(s) to whom you are communicating and the content of the communication.
• I will demonstrate respect towards all parties involved in the communication process.
• I am accountable to you for the services I provide within the boundaries of my role as a communication assistant.
• I will act in a professional manner, follow the ACCPC training guidelines for a communication assistant and incorporate your specific communication support directions.
• In circumstances where I cannot provide the highest standard of service, or where I feel there is a conflict of interest, I will inform you and, if possible, assist you to secure services of another suitable qualified communication assistant.
I, (**name of person who uses AAC**), agree to respect the ethical guidelines outlined above for communication assistant services. In addition, I agree to abide by the following ethics:
• I take full responsibility for my communication and what you communicate on my behalf as directed by me and in my presence.
• I will provide you with as much information as necessary to support you in knowing how I communicate and what I want you to do when assisting me to communicate with another person.
• If necessary, I will book additional time with you to prepare for a communication event.
• I will inform you about the type of communication assistance I may require within a situation.
• I will follow the guidelines to ensure an adequate working environment, to book and cancel appointments, to allow for sufficient breaks and to negotiate assignments that are longer than 2 hours.
• I will respect your role as a communication assistant and not ask you for your opinions, advice, or to act as an advocate, coach or personal care attendant.

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ticipants used the communication assistants, although the frequency varied. Usage increased as the project progressed. Participants who could generate unlimited messages or who used speech as their primary means of communicating were the most frequent users. Participants with limited access to vocabulary used the services less frequently and required more support to plan and book the services.

Participants requested assistance in hospitals, at meetings and workshops, in social situations, with neighbors, at home on the phone, to search out community services and events on the Internet, as well as in the community to do business in banks, restaurants, shops, *etc*. Communication assistants developed context-specific communication tools, co-constructed and delivered messages, interpreted impaired speech, prepared messages for upcoming events, helped with phone calls and supported interactions with community service personnel.

Outcomes. Overall, participants reported that communication assistant services had significantly increased their community participation. They also said more people had learned how to communicate directly with them and that assistants had made it easier for them to communicate, especially with doctors, lawyers and counselors. Participants noted they now had more opportunities to communicate and were receiving better commu-

nity services. Everyone appreciated the training provided. An example of the agreements that communication assistants and individuals who rely on AAC signed is shown in Table IV.[28]

Lessons learned: The funded project has ended and ACCPC is currently negotiating the need to replicate these services across Canada. The plan is to implement a three-year project to further study the components, outcomes and costs of communication assistant services. ACCPC offers trainings, resources and consultations to groups starting communication assistant services.

For more information, go to www.accpc.ca or contact Barbara Collier at barbara.collier@sympatico.ca

SWEDEN: Interpretation Services for people with CCN.[32] The Swedish Health Department has offered interpretation services to people who are deaf since 1976. In 1986, one county in Sweden began offering interpretation services for persons with CCN, which became known as the Swedish Speech Interpretation Service (SSIS). People with amyotrophic lateral sclerosis, cerebral palsy, stroke, multiple sclerosis, Parkinson's disease, stuttering and other conditions affecting speech qualify for these services.

Today (30 years later), interpreter services are available for people who rely on AAC in 11 of Sweden's 21 counties. The Swedish Health Department funds these programs as a public service. Access to interpreter services varies.[32] For example, in some counties individuals can book interpreter services for evenings or weekends, while in others interpreters are available only on weekdays.

SSIS interpreters are primarily professionals (speech-language pathologists and occupational
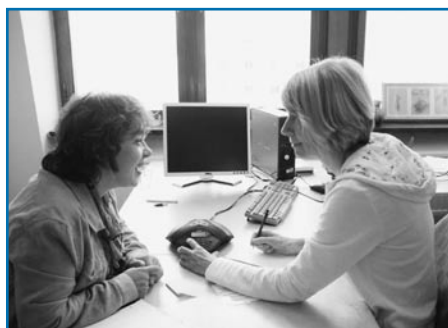
This woman is getting support from a speech interpreter to make a phone call.

therapists) who provide (1) vocal support (the interpreter translates fragmentary or unintelligible speech into an understandable message); (2) reading support and/or (3) writing support. Interpreters support the use of speech generating devices, Talking Mats™ and other low-tech/no-tech strategies.

While no formal education is required for SSIS interpreters, many have taken courses in AAC, ethics, the role of an interpreter, *etc*. In addition, they meet as a group during a yearly national congress, where a code of ethics for SSIS interpreters is currently being drafted.[32]

SSIS for people with aphasia. Inger Larsson and Anna-Lisa Thoren-Jonsson, researchers from Goteborg University and Vardal Institute in Sweden, embarked on a study to ascertain the opinions of people with aphasia who had taken advantage of professional SSIS interpreter services for at least six months.[33] The goals of their study were to explore factors that led individuals with aphasia to engage a professional interpreter and the degree to which SSIS interpreters were perceived as respecting the individual's feelings of autonomy.

Participants. Twelve people with aphasia participated. All had used professional SSIS interpreters for between six months and 14 years, with a mean of five years. These individuals relied on a range of

communication means and modes (speech, gestures, drawing, pictures and human supports) to express themselves.

Participants were interviewed for one to two hours in their home or an SSIS office. Questions related to each person's (1) reason for choosing to use SSIS services, (2) experience with professional interpreters, (3) opinion about the differences between using professional interpreters and receiving support from friends and relatives and 4) general feelings about professional interpreters.

Results. Researchers analyzed transcripts from the 12 interviews, and reported on two major themes.

1. *Purposes of using interpreters*. Participants used interpreters in multiple contexts to accomplish a variety of goals (*e.g.*, make a will, shop, participate in cultural activities or meetings, read/write letters or emails, interact with authorities or public officials, *etc.*). They reported that interpreters maintained their autonomy and privacy, gave them control over when and how to communicate and did not overburden family members.

2. *Perceptions of service quality*. Participants appreciated when interpreters checked with them in advance of a meeting or appointment to discuss details and prepare materials. The interpreters knew about a range of AAC strategies and understood the nature of aphasia. Participants with aphasia perceived professional interpreter services as superior to services provided by their relatives, friends, relay operators and personal assistants. They valued the professional behavior of interpreters and felt their privacy was respected. They also appreciated the neutrality interpreters maintained during interactions (*i.e.*,did not express personal opinions or take sides).[33]

Results of the study demonstrated that SSIS interpreters offer services that people with aphasia value. As a result, Inger Larsson says that she and her colleagues will continue to advocate for the SSIS program throughout Sweden.[32]

For more information, contact Inger Larsson at inger.ma.larsson@vgregion.se

Summary

It's refreshing to discover pockets of progress in Finland, Sweden, Canada and Australia. But, at the same time, it is discouraging to realize how long it is taking the rest of the world to understand, accept and support this fairly obvious extrapolation of rights long secured by individuals with other disabilities.

People with CCN should have equal access to the kinds of human supports that have long been available to individuals with sensory impairments. It's time for us to resolve to step forward and follow the lead of our forward-looking colleagues. The AAC community needs to demand equal rights for individuals who rely on AAC and demonstrate in more places the practical steps required to make communication assitant services a reality.

AAC-RERC
SPREAD THE WORD

The Human Element
by Johana Schwartz

I am a professional writer, skilled at using my communication device and computer. However, I still recruit and hire an administrative assistant and use resources such as Speech-to-Speech relay services.[38] As the manager of the AAC-RERC Writers Brigade,* I telecommute over the Internet sixteen hours a week. My job is to coach people who use communication devices in technical writing. I assign writing to participants, edit their work and submit their finished articles for publication.

I primarily use a communication device called a Pathfinder, which is incompatible with the oper-

Johana Schwartz with her assistant Karina Kuhrt

ating system on my computer. I use a head mouse, but do not have the fine motor skills to place the cursor on tiny buttons on the World Wide Web. Furthermore, my onscreen keyboard works one letter at a time, so it does not have the capacity to keep up with the pace of the job and the volume of writing required. My administrative assistant helps me fill in the technology gaps and do my job more efficiently, increasing my productivity. A human assistant can provide more short cuts, flexibility

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* An AAC-RERC project, carried out by Augmentative Communication, Inc., and funded by the National Institute of Disability and Rehabilitation Research (NIDRR). www.aac-rerc.com

and spontaneity than automated systems such as "Macros" or "Smart Inboxes."

My administrative assistant acts as a scribe and assists me to access the computer and paperwork while I work. I privately hire the assistant and can deduct the cost as "impairment related work expenses." She comes to work at my residence during my office hours. This person does not function as a personal care attendant. Under my direction, she writes as I dictate. I use a combination of my communication device and natural speech while my assistant uses my computer with *Microsoft Word*, especially the 'Track Changes' feature. The assistant also helps me navigate through my webmail and set up emails with addresses, attachments and messages. Finally, at my request, she searches the Internet to conduct research and find materials for lessons.

Making life easier

The job description for my assistant includes handling, filing and occasionally responding to email, mail and printed materials associated with the Writers Brigade. She advocates my interests over the telephone and in person by making appointments, interpreting my speech, or recounting what I had stated before. This saves me time and energy. In addition she takes notes during meetings or telephone conferences.

I recruit assistants by word of mouth at local rehabilitative facili-

ties, such as the Courage Center, and through the University of Minnesota's Goldpass (https://goldpass.umn.edu/), an online database aimed at connecting students and alumni with employers, volunteer organizations, and internships across the country. Through these organizations, my job announcements for an assistant reach a broad network. When applicants respond, I review their resumes and consider their qualifications. I call and schedule interviews for applicants I find impressive.

College students or recent graduates are ideal for the position of administrative assistant because they offer their college-honed skills of researching and typing. Prospective assistants with backgrounds in languages and linguistics may find it easier to understand my speech since, as I like to say, *it is just another accent to get used to*. Assistants with background in sociology, psychology and pre-law may be able to apply their skills in advocacy. I hire assistants who show an eager interest in helping to make my life easier and more functional. Some have family members who are in similar situations; however, that is not a requirement.

Branching out

My administrative assistants open up many avenues and countless possibilities. I can utilize them for enhancing the professional, social, personal and educational aspects of my life.

1) They are companions in an otherwise isolating situation that sometimes comes with telework. The addition of an administrative assistant transforms a lonely room into an office. The assistant keeps me structured and on schedule. It is encouraging to have the ability to discuss or brainstorm my executive decisions with a person face-to-face.

2) They expand my network by introducing me to people I would not otherwise meet.

3) I am better connected with my friends and family members because I have a greater ability to keep in contact with them.

4) My assistant allows me to take advantage of community resources by driving me to places I need to go, enabling me to run errands and so on.

Overall, with an assistant I can focus on my job and do things I probably would not do otherwise.

When my assistant is unavailable and I need to make a phone call, I use the Speech-to-Speech (STS) relay service called Minnesota Relay. It is a free service and available in any state and most countries. STS allows people who have speech disabilities to communicate over the telephone. An STS operator receives my telephone call and dials any phone number that I give. The operator stays on the line while I conduct my conversation and repeats what I say with astounding accuracy. The operator also helps me keep up with computerized automated menu systems (*e.g.*, "Press 1 for English, Press 2 for Spanish"). Also, the STS operator can recount information I have already given to save time without delaying or influencing the direction of my phone call and can provide continuity when my call is redirected.

Summary

Communication assistants supplement my assistive technology. A live assistant can think critically about, and adapt to, different situations by keeping my background and intended outcome in mind. A good assistant not only develops an understanding of my needs and goals, but also understands specific situations we encounter together. Thus, an assistant can become a valued advocate who anticipates certain obstructions without my telling her what to do.

Speech to Speech (STS) Relay Services

Individuals in the United States (and its territories) and several other countries who have difficulty being understood on the telephone can access a free telephone services called STS. STS employs trained communication assistants who are skilled at revoicing unclear or quiet speech and can support the use of speech generating devices in telephone calls. Some STS programs refer to their communication assistants as operators. STS services are available 24 hours every day so an individual with a speech disability can make and receive calls.

STS communication assistants are trained to understand a variety of speech patterns and to process all calls with patience. Assistants revoice the words of the person with difficult to understand speech. All conversations are confidential. The communication assistant may revoice all or just some portions of the conversation.

A caller dials the STS relay toll-free number (711 in the United States) and asks for STS services.

Note: In 2006, the University of Wisconsin - Madison awarded Robert Segalman, Ph.D., an honorary Doctor of Science for his work in creating Speech To Speech.

Resources

Sincere and hearty thanks to the following individuals for their insights, participation and help.

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14 www.un.org/disabilities/default.asp?id=150 Download Convention and Optional Protocol in HTML or PDF format. Go to Page 4. Accessed on September 10, 2008.

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