



This issue's spotlight article shines on AAC and aging. Although the bulk of AAC research has been focused on children and youth, older augmented communicators find themselves facing unexpected problems as the result of the aging process. These challenges can result in uncertainty, anxiety and aggravation.

Changing times

On one hand, technology is advancing at a faster rate than ever. There are roughly one hundred communication devices on the market with all kinds of features to fit various needs. These devices are becoming more and more portable, versatile and reliable. Available funding sources, once almost invisible, are becoming noticeable.

On the other hand, AAC systems remain far too complex, stigmatizing and costly, especially for older users. Obtaining funding for AAC devices becomes more difficult as users age. Patience for bureaucratic red tape wears thin. This problem is intensified by the reduced amount of advocacy efforts on behalf of older AAC users. While many children have moms and dads as their chief advocates, often times older AAC

Aging and AAC

consumers depend on spouses, siblings or adult children to provide this support. These family members may lack the drive, time or sensitivity to be effective advocates. As a result, all too often, the familiar word "no" is accepted.

Obtaining an AAC device

AAC is still too new a field to be widely accepted in many medical circles as an appropriate intervention for older clients with severe speech disorders. Most research on AAC systems does not fit the scientific and medical mold that many health care professionals, insurance companies and government agencies require in order to recommend an intervention.

The literature upon which medical professionals rely is especially lacking in AAC research. Positive outcomes, improvements in quality of life and cost-benefit analysis of AAC interventions are inadequately documented in the research. Without these publications, it is very difficult to obtain support from medical stakeholders. Progress has been made on this front. For example, Medicaid (US health insurance program for the poor) in many states and some private insurance plans will purchase AAC devices on a limited scale. Medicare (the major US health insurer for the elderly and people with disabilities) still does not cover AAC devices; however, this policy is currently being reviewed.

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Message from Michael

It's the year 2000, and the dawn of the New Millennium brings changes to *Alternatively Speaking*. With this issue I assume the title of editor rather than author. This will allow AS to present its readers with fresh voices with fresh ideas. But this doesn't mean I will be retiring to my rocking chair by the TV set. On the contrary, the change in title will give me some opportunities to spar with and cajole some of the best whippersnappers in the business.

We lead off this new arrangement with an issue written by Mick Joyce and Bill Lee. They open and peer into the mysterious black box called aging.

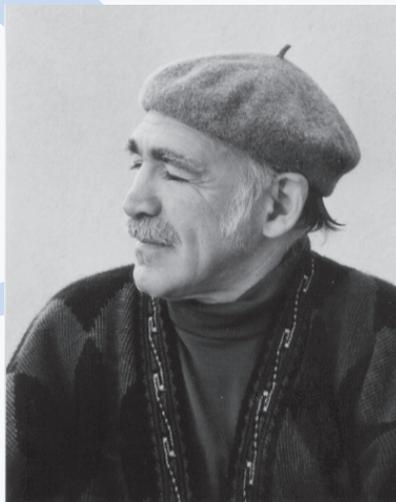
When I was in my youthful forties, my wife jokingly said to me that I wouldn't have to worry about being the father of teen-aged children because I'd be dead by the end of my fifties.

Fortunately my wife is no psychic. A new century is here, I'm well into my sixties, and I'm staring my son's teenage years square in the face.

I've discovered aging with multiple disabilities is no fun. But aging is part of life's cycle; it can't be ignored or delayed. Old age will come to us all, and the sooner we begin to look into the dark corners of AAC and aging, the better we can cope with old age.

We hope this issue of *Alternatively Speaking* is a tiny step in this direction.

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Due to these factors, many older people have restricted access to AAC intervention and treatment, especially those who have newly acquired communication conditions.

Accelerated aging?

The question is, do disability traits progressively worsen as aging occurs? The theory of accelerated aging implies that they do over time. In most disability groups, however, this is yet to be documented by any systematic body of research. It is safer to say that physical, psychological and social forces work together to intensify the normal processes of aging.

An aging voice

The primary reason for owning an AAC device is unintelligible speech. The intelligibility of speech can vary with fatigue, degree of spasticity and other factors. For most people, an AAC device augments natural speech. One does not become mute upon obtaining an AAC system.

Speech for all people slows and becomes less efficient in later years. Many older adults experience problems in the "motor" production of words and sentences. Muscles in the mouth, tongue and throat become less able to respond quickly. Breathing is less forceful for many, and memory is not as sharp. Additionally, communication skills may diminish because the individual simply doesn't hear well.

These factors in combination may make coming up with the right word at the right time more difficult than ever for people who rely on AAC to communicate.

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Choking & aspirating

The muscle groups used for eating, swallowing and other vital activities weaken over the course of many years, causing people to choke more easily. AAC consumers who do not recognize this physical change and do not explain it to their carers may be at risk of developing pneumonia as a result of aspirating food. Forty-two percent of the deaths in cerebral palsied people are caused by respiratory disease.¹ Research is needed to investigate the relationship between swallowing difficulties and aging in people who use AAC devices and strategies.

Staying healthy

A prerequisite to healthy aging is effective communication. As one ages, contacts with health care professionals increase. Data from the United States shows a steady increase in the rate of visits to hospital outpatient departments starting at age 44 years, with significantly more visits by women.² Routine medical examinations and screening tests become critical as tests and preventive interventions can save pain and prevent costly procedures later in life. This is true for the general population, and conventional wisdom implies that it is also true for AAC users.

One report cites seven areas of specific concern for older people with disabilities.³ They include exercise, women's issues, emotional and psychological issues, managed care, dissemination of research, sexuality and communication. Three investigations

showed concern that doctors were not well trained, had poor attitudes and skipped over routine procedures in people with cerebral palsy and other similar conditions.^{3,4,5} Unless these consumers are extremely assertive, many of their needs are unlikely to be met. In order to be forceful in the medical environment, one needs to communicate effectively; people with severe speech and physical disabilities need a reliable, versatile AAC device and effective communication strategies. With age, visits to the doctor become increasingly vital and communication devices increasingly essential.

Exercise

Regular exercise and proper nutrition are important for people with disabilities. A good general fitness level includes maintaining range of motion and flexibility; however, under mounting evidence that some exercise is good for older people, little advice is offered as to what exercises will not add to the wear and tear that is predicted in the accelerated aging model. One has to be careful not to overwork already stressed muscle groups. Exercise to improve cardiovascular fitness may improve endurance and help age-related changes that lead to fatigue, but it is unclear how to accomplish this.

Women's issues

Women with cerebral palsy and similar conditions often have problems obtaining routine PAP smears, bone density scans, breast examinations (mammography in particular) and rectal examinations because examination equipment, as well as medi-

cal examiners, often cannot easily accommodate women who are spastic, have contractures or cannot remain still for a significant period of time. Ways are needed to position an AAC device so it's usable during examinations. Issues relating to menopause raise another major area of concern.

Emotional and psychological issues

Depression, anxiety and the loss of self-esteem associated with decreased independence may be troublesome, especially for people with severe communication disabilities.

Psychologically speaking, AAC users experience higher rates of depression,^{6,7} isolation⁹ and stigmatization⁹ than other groups in the population. This pattern causes misplaced feelings of guilt, anger and antipathy which tend to build during the early years of aging and, in most cases, subside during the later years. Thus, hopes, dreams and aspirations⁷ slowly fade into the sunset of each passing day. Granted, this phenomenon occurs, more or less so, in many people as they age, but it is much more pronounced in people with disabilities in general and in AAC users specifically.

Sexuality

Little research and few resources related to understanding healthy sexual expression in older people with disabilities are available. We have limited information about whether sexual functioning fits the accelerated model of aging. Since glands and the autonomic nervous system control many

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sexual functions, the decline may not be as steep as it is thought to be in muscle groups.

As with most concepts in health and disability, a holistic approach to understanding sexuality is advocated; however, it is difficult for many doctors to think in these terms. The concept of sexuality, indeed, has physical components; however, psychological, emotional and social concerns override physical issues, especially since there is a high incidence of rape and sexual abuse among people with disabilities. Topics such as sexual desire, mistreatment, and sexual satisfaction seem to come up less frequently in AAC users than in the population as a whole and are virtually absent from professional AAC discourse.

Role displacement

Socially, many AAC consumers experience a progression of role displacements as they age. From poster child to courageous student to dedicated, hard-working employee to older worker, the progression becomes more manifest. For AAC users whose role(s) may not be well defined in the first place, the onset of aging can bring further displacement and social confusion.

Aging supports

With age may come the loss or fragmentation of a comfortable social support system. Loss of a loved one or a decrease in the abilities of people one has depended upon for support may add to the stress and anxiety of AAC users.

Transitions

Life transitions are of great significance and may interact with other

health related responses. For example, the death of one or more parents may make an augmented communicator vulnerable to outside forces. Parents of AAC consumers often act as advocates, and it is not easy to replace them. Additionally, as time passes, friends and associates move away or die. Communication skills are essential to make new friends and maintain a support network.

Communication breakdowns

AAC devices and other assistive technology can improve communication, but this technology may bring its own set of barriers. Older adults may be physically unable to manipulate a sophisticated device. Some may be reluctant to use assistive technology. Even non-electronic technology may be undesirable or unavailable.

Research is needed that would make AAC and other assistive technology devices easier to operate. Researchers should suggest ways to ease the emotional reluctance to use a communication device, especially for those who acquire speech disabilities in their later years.

Self concept

For older people who suddenly acquire the need to use AAC, the use of any assistive device can carry a stigma and be a symbol of dependence. Any suggestion of dependency implies nursing home placement, which happens to be one of the top fears and causes of anxiety in older people. Moreover, many doctors are reluctant to prescribe AAC devices since they are not aware of

or knowledgeable about them. Unfortunately the literature on AAC and aging contains slim evidence of positive outcomes, health improvements, improvements in quality of life or the benefits of AAC intervention outweighing the costs.

Forethought

Aging is a natural part of life, whether one is an AAC device user or not. Like all of life's transitions, the aging process has its ups and downs, ladders to climb and descend and times of intense joy and sadness. With a little bit of forethought and a big sense of humor, many AAC users can meet whatever unique challenges, snags and needs aging may present.

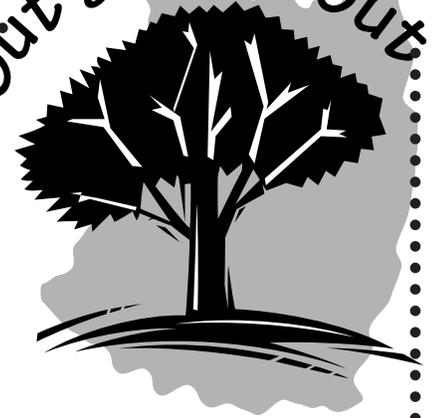
Conclusion

The aging of augmentative and alternative communicators reminds one of the Charles Dickens' novel, *The Tale of Two Cities*. Recall those famous words, "It was the best of times, it was the worst of times." For the aging AAC consumer, it can be a time of uncertainty, anxiety and aggravation; however, it also can be a time of great expectations, anticipation and optimism. As more augmentative and alternative communicators approach the "age of wisdom," those in the field of AAC must turn their spotlights on aging. Full inclusion, communication and disability rights are not only the purview of the young.

by Mick Joyce

Internet Links

Out and About



Here are five websites on aging with a disability which I find useful.

Mick Joyce

Clearinghouse on Aging and Developmental Disabilities

<http://www.uic.edu/orgs/rrcamr/index.html>

The Clearinghouse provides a wealth of resources for anyone interested in disability related issues. This is great for a quick listing and descriptions of materials published during the past ten years by researchers of the Rehabilitation Research and Training Center on Aging with Mental Retardation.

Health, Wellness and Aging with Disability

<http://www.jik.com/hwawd.html>

This site covers what is currently known; lists new realities; raises new concerns regarding health, exercise and maintaining functional abilities; asks many research questions; advocates for health reform and more; references best information and guidelines; lists health services, assessment and evaluation guidelines; calls for a national information and dissemination network; explains role of independent living centers and other disability-related organizations; tells horror stories; gives tips for weighing whether you'll use the gear; provides definitions; includes resource lists and recommended readings.

Aging With a Disability

<http://www.agingwithdisability.org/>

This site investigates the impact of aging upon persons with a disability, examining issues such as health changes, psychological reactions, family needs and job accommodation.

CPIC (Cerebral Palsy Info Central)

<http://www.geocities.com/HotSprings/Sauna/4441/CPIC.html>

This consumer site provides a wealth of information so that people may learn about cerebral palsy and how it affects people throughout life.

Susie's Cerebral Palsy Resource Pages

<http://www.susiecp.com/CPresourcepg.html>

A consumer site with a lot of insight on cerebral palsy and related issues, such as aging.

Healthy Aging in Adverse Circumstances

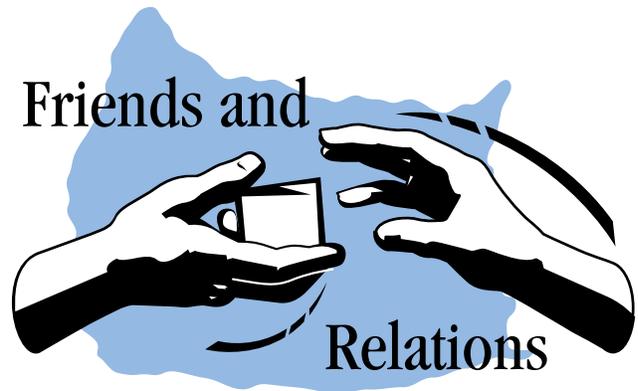
It is very difficult to maintain a positive attitude toward the health care system and a society which implies exclusion rather than inclusion of people with disabilities in normal day-to-day activities. One organization which is very aware of this issue is the Ontario Federation for Cerebral Palsy.

This Federation is a non-profit organization of about 40 member groups throughout Ontario that address the changing needs of people with cerebral palsy and other physical disabilities, while recognizing the inherent dignity and rights of all individuals. In 1996 the Federation published a report entitled *Aging, Well-being and Cerebral Palsy*.⁸ This report compares people aging with cerebral palsy to those aging with other disabilities. It found that aging with cerebral palsy has more profound effects than aging with many other disabilities.

While issues of aging and cerebral palsy have begun to garner interest, the factors that account for the well-being of people with cerebral palsy as they become older are not well known. *Aging, Well-being and Cerebral Palsy* addresses this knowledge gap. The report lists many things persons can do to improve mental health. Some are listed below.⁸ The full report can be found at <http://ofcp.on.ca/aging>.

Mick Joyce

- Keep the mind active.
- Do something new.
- Maintain a good outlook on life.
- Scream, yell, or sing while bathing.
- Don't stop thinking about tomorrow.
- Be open to new learning experiences.
- Stay away from fatalism; take control of one's situation as much as possible.
- Think of oneself as beautiful and sexy.
- Use the system as much as possible.
- Put a little love in your heart.
- Continue to dream, even if dreams seem unrealistic.
- Always look for new friends.
- Show respect for people, smile and say "Thank you" even if you don't mean it.
- Be assertive while accessing services.





Dependency

Having a disability exacerbates the aging process in more ways than one. For example, doctors seem reluctant to order diagnostic tests for people with disabilities. I attribute their reluctance to either not wanting to put me through the discomfort of the test, or thinking “he’s not gonna be around for long anyway” (a self-fulfilling prophecy).

For a number of outpatient tests, I believe I require inpatient preparation. Let’s take the lower GI exam I recently needed as an example. The “prep” is a two-day process. The first day, I was instructed to stick to a light diet. The second day, I was to combine a liquid diet with a laxative and lots of water every two hours. Two hours before the exam I was expected to take the infamous Fleet Enema. Since I have CP and can’t use the bathroom easily or quickly, I soon learned the meaning of being “up a creek without a paddle.” Nonetheless, if a test is needed to rule something in or out (no pun intended), then there has to be some mechanism for getting the test and the prep done at minimal cost.

I am an aging child of an eighty-one-year old civil servant. Until I was 19 years old, my parents, siblings and I moved often. However, since 1964, I’ve been living in a small apartment in my parents’ house, except for the three years I was in college at the University of Wisconsin. Over the years, my space in the house has evolved to meet my needs. This space is my home and my anchor, and I want to spend the rest of my life in it. Unfortunately, I don’t own the house or my apartment; my aging parent does. I have no idea how long I will be able to stay in my home.

Another example of how disability exacerbates the aging process is the role reversal and displacement which can occur when family members age. I have depended on my mother for years. The reality is I am finding it more and more difficult to do things, and my aging parent is in the same boat. I cannot provide the support and care she will need. Dealing with our aging, arrangements for the future, emotional issues and family members who may choose denial over action is difficult at best.

Convincing siblings it’s time to get more help for parents can also present a problem. Not knowing the details of a will is threatening. This situation is painful to deal with. Personally, I feel I am too close to be objective or effective . . . somewhat like trying to be my own doctor.

Complications arise when there is no clear plan for the future. It can be difficult and uncomfortable to plan ahead, but when it comes to dealing with parents, siblings and other people, I suspect it would be easier than waiting until the last minute and finding oneself in a quagmire of emotions and legalities.

by Bill Lee

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AAC-RERC: Projects on Aging

Just over a year ago, the National Institute on Disability and Rehabilitation Research (NIDRR) announced a 5-year grant to fund an Augmentative and Alternative Communication Rehabilitation, Engineering and Research Center (AAC-RERC). The new AAC-RERC takes a multi-site, collaborative approach to research and engineering to improve technologies and strategies that make a difference in the lives of people who depend on AAC to communicate. The AAC-RERC is "virtual" and therefore, can take advantage of leading researchers in the field through a multi-site collaboration.

Several projects pertinent to the topic of aging are funded under the direction of Dr. David Beukelman at the University of Nebraska. One of these projects focuses on the impact of attitudes toward AAC users when

they use different forms of communication (their speech, a low-tech AAC notebook and a high-tech AAC device). The researchers are making three videotapes. One is a video of an individual with amyotrophic lateral sclerosis (ALS) communicating with a partner. The second video depicts an individual who has aphasia, and the third shows someone with Parkinson's disease. In each video, an individual tells a story to a partner using (a) residual speech, (b) a low-tech AAC notebook and (c) a high-tech AAC device. The ALS tape will be viewed by (1) individuals with ALS who use AAC, (2) their peers, (3) their family members and (4) service providers who work with individuals who have ALS. Groups viewing the other tapes will be similarly configured. Subjects will answer questions about their attitudes toward each method of communication and rank order their preferences.



Then focus groups will explore reasons for these rankings.

In addition to the University of Nebraska, six other sites are part of the AAC-RERC team: Duke University Medical Center, Pennsylvania State University, University of North Carolina at Chapel Hill, University of New York at Buffalo, Augmentative Communication Inc. and Temple University.

For more information, check out ACI's new website @ <http://www.AugComInc.com> and the AAC-RERC website @ <http://www.aac-lerc.com>