ALTERNATIVELY SPEAKING

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Love and Marriage

People who use AAC expect to take on the privileges and responsibilities of adulthood: independent living, control over finances, employment and adult friendships, including intimate partners and perhaps marriage. Many individuals who rely on AAC have demonstrated success in these adult roles. This issue of *Alternatively Speaking* takes a look at long-term, intimate relationships and marriage.

It is almost always easier for a person who uses AAC to be single, but easy is not what marriage is about. Most supports that are set up to make living with a disability easier—from housing to education to home care to government benefits—are set up for single people. A partner gets in the way of how things usually are done. Some of the marriage disincentives are systemic, others are social.

Benefits and services

If either partner receives any disability services or government benefits, the spouse is required to disclose as much personal and financial information as the individual who receives the services or benefits. These reporting requirements can be quite startling to someone who is unfamiliar with the lack of privacy in disability systems.

Some disability benefits and services require that the income of both partners stay below a certain level and, in fact, are less forgiving of an able-bodied partner's income. Partners of people who receive government benefits or social services must be able to handle the intrusion of service agencies and their representatives, and the poverty these systems encourage.

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A disability benefits counselor can offer good advice. In the United States, for example, the benefits rules for people with disabilities who are married are very different from the single individual rules. A disability benefits counselor who understands these rules can be invaluable. Look for someone who not only can explain the marriage rules of programs and benefits you participate in, but who can also explain how these rules may interact. Sometimes losing benefits or program eligibility is not a problem, but losing the accompanying health insurance, which pays for medications, assistive technology and medical treatment, has a very negative impact. A good disability benefits counselor can also explain how much of your business and your partner's business is any agency's business.

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Message from the editor

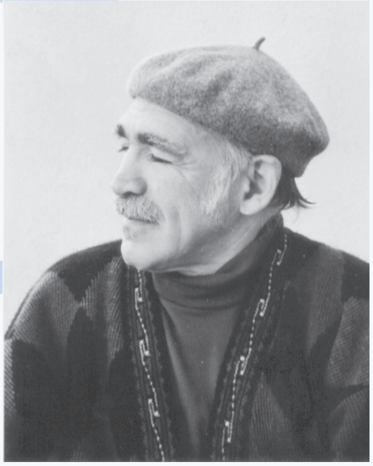
Sometime in the nineteen-fifties I had orthopedic surgery on my feet. During the lengthy recovery period, I spent many hours listening to music on the radio. Radio then wasn't like radio today where everything is geared to the teenage market. The airwaves then were infused with the sounds of sticky-sweet love from middle class suburbia. These messages were intoned by such full-throated warblers as Jo Stafford, Doris Day and Frank Sinatra.

It was Sinatra who filled my ears during that period of recovery. He had a smash hit called "Love and Marriage," and you couldn't go five minutes without hearing it on some radio station. I used to be able to quote the entire song by heart, but the intervening years have been kind—now I can only recall the first lines: "Love and marriage, love and marriage/ Go together like a horse and carriage."

I didn't believe those words for a minute. Maybe love and marriage went together for some people, but certainly not for a disabled person such as me. I knew nobody would ever love me except my sainted parents, so better put all that stuff out of my mind.

Well, that was the nineteen-fifties. Today, people with disabilities, including people who use AAC, are falling in love and getting married. This is what this newsletter is all about. As you will see, the road of love may be rocky, but that is no reason not to take the journey.

I write this knowing I have twenty-five years of marriage under my belt, and two children in the bargain. "What happened?" you ask. The answer is in an old Nat King Cole song: "I was walking along, minding my business/ When out of an orange-colored sky/ Flash! Bam! Alakazam!/ Wonderful you came by."



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In-home workers

Social barriers are probably the most unexpected and frustrating. An example would be the attendant who is no longer willing to clean the shower now that your girlfriend also uses the shower. Managing in-home workers is much harder when you are sharing a life with someone. As usual, information is key. A social worker, disability advocate or omsbudperson can explain your rights as a client of any program. Ask questions. "What choices do I have?" "What are the standards for workers to respect my privacy?" "As a client, am I allowed to independently make decisions about friendships?" "Are there standards for how agency employees should treat my friends?" "What rights do I have?" Ask whatever questions are important to you.

Hiring people to work in your home is difficult as a single person, harder as a couple and even harder as a couple with children. The prospective worker has to be comfortable around both partners and accept the relationship. Children complicate things even more. People tend to feel strongly about the "right way" to raise children, and may find your child rearing techniques unbearable to observe.

Control and autonomy

People with significant communication disabilities usually have close relationships with a multitude of care providers and an extensive medical support network of pharmacists, physicians, therapists, assistive technology technicians, social workers and other service providers. A partner may be surprised that he or she is not only marrying into a family,

but also taking on a system of supports, and may be amazed at how many people have some degree of decision-making authority. While limiting the helping people who have some say in what you do may provide more freedom, it also results in fewer services.

Professionals often expect clients to be compliant. An adult who knows what he or she wants may be perceived as noncompliant. The compliance requirement may be difficult for a partner to understand. Compliance is a hidden cost of social services.

Sometimes the support network is resistant to the idea of intimate friendships. Who the partner is does not matter. That there is a partner is the issue. Writing down your expectations of professionals and care providers may be useful. This might include, "Support me to develop friendships." "Respect my right to make adult decisions." "Do not talk about me in front of me like I am not here." "Respect my privacy." You know what you want from them. Give them the words you want them to say.

In the spotlight

It is highly likely that a couple consisting of one or two people who rely on AAC will be unique in their community. This uniqueness has three results. First, the reassurance and support that comes from knowing similar couples will be limited. Second, the couple may be perceived as a model and an example for others. They may feel like they are on display. Third, the attitudes of strangers, friends and family members may not be as expected. Since marriage and intimate friendship are not typical roles for anyone with a significant disability, people may find it difficult to understand the relationship. They may rationalize that one partner is after the money, is up to no good, is crazy or is hoping to get lots of sex or a baby. They may expect the partner who relys on AAC to be grateful for the relationship and to accept less than ideal behavior in a partner.

The partner of a person who uses AAC must become very clear about his or her role in the relationship. Each couple develops a way of balancing their coupleness with a system of supports. Both partners must be able to clearly articulate roles and boundaries, not only to each other, but also to people in their community. If you don't define your relationship, others will.

Virtual disability

The social status of both partners in an intimate relationship is likely to be the "tainted" status of the partner with the most noticeable disability. This can be very confusing to a partner without a disability. It's not about the individual at all. It's about politics, prejudice and culture. Paying attention to your social networks as a couple will ensure that both partners have a robust group of friends, associates and colleagues to share in their lives.

Marrying someone who uses AAC may be the ultimate mixed marriage for a person without a disability. There are going to be lifestyle issues. Are you dreaming of a sexy little car that purrs around corners or a powerful van with automatic tie downs and an electric lift? Is that savings account earmarked for a week on a tropical isle or for a fast new wireless computer?

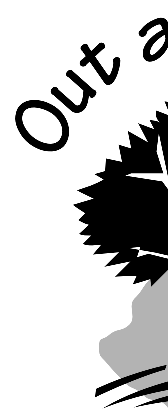
There also may be conflicts over time. Everything seems to take longer with a speech disability, yet many things have to be done right on schedule. There isn't a lot of dashing around as the mood strikes.

Adapting to the look and feel of environmental access in the home may also challenge preconceptions of the ideal. Some partners are going to be uncomfortable with all the assistive technology: wires, devices, chargers, manuals and computer disks all at the ready. The lack of privacy and control in ones own household can be overwhelming. Reading the newspaper at breakfast or enjoying a novel before bed may not be exactly as expected.

Friends and family members may have trouble adjusting their stereotypes. Their homes may not be accessible. Participating in activities and sports, going dancing, enjoying public spaces, patronizing shops, enjoying the theater, eating at restaurants all contain access challenges.

Conclusion

People who rely on AAC and want a lifelong intimate partner will face many barriers. Very few of these barriers have anything to do with communication. Some of them are just part of living with a significant disability, but many are unnecessary barriers created by an unthinking society. Whatever the source, these barriers present a challenge to intimate partners.



A Conversation with James and Melissa

Melissa: When I first met James, I thought he was just some hot guy in a wheelchair who liked to pop wheelies. I didn't even like him. He didn't say much, just a few swears that you could barely understand here and there. That was James to me. He couldn't speak, but I remember his expressive eyes. We were married a year later.

James: Melissa and I first started our relationship by email. I was looking for a friend to talk to, and we fell in love. I saw myself as a normal guy with Melissa and not as a disabled person.

Melissa: Communication with James and me is lots of different things. It is unique, exciting, frustrating, tiring, amazing, fun and beautiful. We communicate in a lot of different ways. All of them are time consuming and take a lot of patience on both our parts. I lose my patience a lot more than James!

James: I feel our communication as a couple is magic. Our communication is lovely, wonderful and hard. Melissa can say what she feels right then and there. I can't. I have to wait to type on my computer to speak my mind. My device is a huge part of who I am.

Melissa: My favorite way to communicate with James is with his communication device. I love talking in person. I love seeing him use his foot to type. I love that I hear his voice. I love being next to him and feeling like a real couple who talks when they get home from work or go out to coffee.

James: I love sitting with Melissa and taking the time to talk. Our communication is the lifeline of our relationship. She and I are best friends, and that is what makes our relationship work.

Melissa: Sometimes it is hard because it takes James a long time to type. Our days are filled with insurance calls and rehab appointments, dinner and laundry. James is often sending out emails to the various places he has to deal with on a day-to-day basis. Time for talking is sometimes eaten up faster than we think. I run around the house between dinner and laundry saying, "Type it up, and I will come read it." I hate that. James hates that. I guess in a way you could say we are like every other couple that has little time to chat!

James: I feel the best way to communicate with Melissa is by email. I feel connected to her a lot. I can take my time and not be rushed. I have a chance to get all my feelings out in the open. Once I email my thoughts, they are easier for Melissa to understand.

Melissa:: As I type this, James and I are using another form of communication. We speak in Morse code. Morse code is fast and is easier to understand (for those who know it) than the single letters that he can say. It took me a long time to learn it. At first I would get frustrated because it took James a long time to get all the dit-daw-dit-daw's out. Morse code became easier over time. We now use it every day.

James: We know that our relationship is normal. No one has to say that to us. People often see us together and they say, "Time stops." I think people say that because they see what we have.

Melissa: No one ever told me it would be easy to be with James. (And no one told him it would be easy to be with me!) We knew communication wouldn't always be a walk in the grass. From the beginning it has been work and we work hard every day to make it work.

James: Every couple has communication breakdowns, but with our relationship it is different because I use AAC. It is really hard to get everything out because I want to say so much but can’t type fast enough.

Melissa: It is not easy for us to “fight.” We don’t yell as a couple. I yell. James types with his switch in a frustrated manner. If we don’t have his device, we try Morse code. Sometimes we have to wait until we are both calm enough to talk, or we wait to get to his computer.

James:: It isn’t always the perfect relationship. We fight. And when we fight, it is hard to say what I feel with my communication device. I don’t really get to say what I want until later. We may fight differently than other couples, and we may communicate differently than other couples, but we are normal in every way.

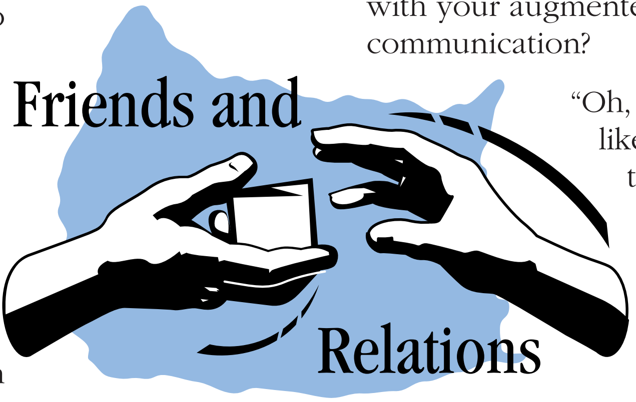
Melissa: We love that we are able to communicate like every other couple, but in our own way. Getting past the tough times is what makes our communication stronger.

James: I love our communication and our life together.

Rick Creech on Marriage:

An Interview with Michael

Rick Creech and I go back a long way. He came to my hometown of Berkeley, California for a conference on AAC sometime in the nineteen-eighties, and he was the first person I saw using a voice output communication aid. Rick is currently employed by the Pennsylvania Training and Technical Assistance Network, PaTTAN, a statewide entity that supports the efforts of the Bureau of Special Education and builds the capacity of local educational agencies to provide appropriate services to students who receive special education services.



Rick and Yolanda have been married almost as long as Carole and I, so I asked Rick for some thoughts on love and marriage for this issue of *Alternatively Speaking*.

I asked how augmented communication affects a relationship. His answer really surprised me. “If a person is going to have a relationship with an augmented communicator,” Rick said, “augmented communication won’t really matter, except it does make communication easier.” Rick nailed down his point by adding, “Augmented communication facilitates communication, and communication does facilitate relationships.”

Then, why is it so difficult for an augmented communicator to form intimate relationships?

Rick said, “The physical and/or mental disability, of which speech is just one aspect, really affects personal relationships. My wife really misses that I cannot do things around the house, drive, walk with her holding hands, etc.”

So your wife has no problems with your augmented communication?

“Oh, she would like if I could talk to her when we are lying in bed; or rather, I should say I would like it since sometimes I think my wife likes being able to talk to me without me being able to talk back!”

Really, your wife has no complaints about your communication?

“My wife’s greatest complaint about my communication is that I don’t talk with her enough,” he said. “However,” he added, “husbands have heard that from their wives since Eve told Adam, ‘Well, if you had explained it, I wouldn’t have been talking to that serpent!’”

So you want to get married?

Finding a life partner begins in the sandbox with finding a first friend. Each friendship leads to the next, and there is always the potential that some friends will become "best friends" or perhaps lifelong partners.

How do I become someone's friend? Lots of people have ideas about this; there are experts, books, models and curricula.[1] Friend-making strategies vary with age, gender, culture and geography. Friendship is still much more of an art than a science. Strategies that meet with success for one person may fail for another.

Certainly, establishing friendships has something to do with communication. This being the case, people who use augmentative and alternative communication (AAC) should have an advantage as they certainly know a lot about communication. On the other hand, lots of people who use AAC don't have as many friends as they would like. It may be that there is more to communication than we understand. From chemical pheromones, to timing and inflection, scientists are just beginning to describe what all goes into a conversation that makes a person likeable.

What does a friendship look like? Everyone has his or her own idea of what makes a friend. Someone who is being paid to be with me may be pleasant enough company, but she is not my friend. Someone who is doing community service or hoping to get to heaven by spending time with me is not my friend. In fact, the ever-presence of these compensated pseudo-friends may actually interfere with the development of true friendships.[2] Additionally, the methods used to teach AAC strategies and techniques probably don't take into account the kinds of subtle communication that nurtures friendships. Since we are just beginning to understand that "men are from Mars and women are from Venus," the cultural and gender gaps between AAC clinicians and many of the individuals who are learning to communicate with AAC may be creating unknown barriers to friendship. Certainly AAC technologies deliver much less than any fan of science would expect.

Friendship can be very confusing for individuals with complex disabilities as friendly people who want to help almost always surround them. Celebrities openly regret how difficult it is to identify true friends, and I say it is no easier for people with severe disabilities. One way to take an objective look at the quality of your friendships is to consider your communication partners. The circles of communication partners chart that *Social Networks*[3] uses breaks down the people you communicate with into five concentric circles, which represent family, friends, acquaintances, paid workers and strangers/unfamiliar partners.

Friendship takes time. People who use AAC and live independently don't have a lot of free time. The management responsibilities of survival and success can be all-consuming. Friendship also requires time away from the staff, helpers, volunteers and family members who support your day-to-day life.

It's a big jump from being friendly at school, at work or in other structured activities to being friends at home. Once a society removes architectural, transportation and program barriers, public integration is not too difficult for an individual, but integration of free time is much harder.

Going to a concert or the movies is fun, but it won't give you a chance to make connections with people unless you take time to sit down and chat before or after the event. Activities that encourage interaction and communication are more likely to lead to friendships.

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Specialized AAC Vocabulary

AAC-RERC
SPREAD THE WORD

by Johana Schwartz

In order to be successful in adult roles, such as work or marriage, people need to be able to "talk the talk." That is, they need to know how to use words that apply to specific contexts. In marriage and other personal relationships, certain words inevitably come up in conversation: date, single, fiancée, partner, sex, pregnancy, intimacy, privacy, birth control. Adults who communicate with devices that contain stored vocabulary will want such words available in their devices for easy access so that they, too, can "talk the talk."

Yet, in 1996 Dr. Diane Bryen,[4] a partner in the Rehabilitation Engineering and Research Center for Communication Enhancement (AAC-RERC), and Bonnie Moulton, a graduate student at Temple University, found that the three most popular AAC symbol sets lack most of such words. In fact, Unity (Prentke Romich Company), Picture Communication Symbols (Mayer-Johnson) and Dynasyms (Dynavox) contain only 5-17% of words commonly used to express intimacy in a variety of personal relationships. Dr. Bryen concludes, "There is a need for vocabulary that is relevant and reflects socially valued roles of adults who use AAC."

In response to this finding, Dr. Bryen, along with co-investigators Kevin Cohen and Rosangela Boyd, all of Temple University, launched the AAC-RERC project, "Specialized AAC Vocabulary Research." The goal of the research is to create vocabulary sets that enable people who use these three systems to speak their minds in a variety of adult situations. So far, a word list for employment has been completed and is available to view or download at http://aacvocabulary.com. Specialized vocabulary of interest to college students is now in development. Coming up next is a vocabulary set relevant to people in intimate relationships, such as marriage. Other categories to be addressed are raising children, managing personal care and reporting criminal incidents.

Watch the ACOLUG listserv for the opportunity to assist in developing these word lists. For each of the word lists, Dr. Bryen and her team will be recruiting three focus groups to participate in a series of online conversations.

For example, three focus groups will work on vocabulary related to personal relationships and sexuality. One of these focus groups will be composed of six to eight adults who use communication devices and who are, or have been, involved in intimate relationships. A second group will consist of six to eight adults without disabilities with experience in intimate relationships. A third group will consist of professionals who are experts on the subject, such as doctors or psychologists. Each focus group will brainstorm to generate a comprehensive list of vocabulary used in the context of marriage or intimacy. Words that appear on all three lists will become part of the final vocabulary set. Dr. Bryen and her team will design symbol sets for these words that are consistent with the patterns used in products sold by Prentke Romich Company, Mayer-Johnson and Dynavox. The symbol sets will be offered to the manufacturers to include in their systems' vocabularies. The sets will also be available to the public, as they are completed, at http://aacvocabulary.com. Check this website regularly for newly posted vocabulary sets.

To find out more about AAC-RERC projects, go to www.aac-rerc.com

To join the ACOLUG listserv, follow the directions at http://listserv.temple.edu/archives/acolug.html

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Sources & Resources

1. The January 2004 issue of *TASH Connections* includes several articles which focus on friendship and disability. Single copies are available from TASH at 1-410-828-8274, ext. 107 or aswann@tash.org

2. Obermayer, Liz. (2004) A special friend versus a real friend. *TASH Connections,* 30:1/2, 18.

3. *Social Networks: A communication inventory for persons with complex communication needs and their communciation partners* is available from Augmentative Communication, Inc. To learn more go to www.augcominc.com or call 1-831-649-3050.

4. Diane Bryen may be contacted at diane.bryen@temple.edu

Johana Schwartz may be contacted at johana.schwartz@stanfordalumni.org

Rick Creech may be contacted at rcreech@pattan.k12.pa.us

Thank you to all of the guest authors, and good luck to Melissa and James!

Use It or Lose It?

My publisher and I would like to know what you do with your issues of *Alternatively Speaking*. I am not talking about the physical pages, but about what's on the pages: How do you incorporate the stories, ideas and information you read in *Alternatively Speaking* into the essence of your daily life? Your subscription will be extended by one issue if you respond to this question on or before August 1st. We are easy to reach by fax, postal service or email.

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You'll notice I use the term integration. That's because most people who use AAC to communicate will want the opportunity to make some friends who don't use AAC. To make friends in a segregated setting requires some time away from staff, and to make friends with people who don't have disabilities is easier if you are the only person with a disability in the group. Otherwise it will be assumed that you are busy with the group of people who look like you.

Trying to build friendships with people who don't understand disability or AAC can be difficult. Many people don't consider people with disabilities to be friend material. This has nothing to do with the individual. It's about stereotypes. The stereotypes are wrong, and it is wrong to take responsibility for them. Finding situations where people can get to know you as an individual can bypass these stereotypes.

No one is going to be able to see past social stereotypes if you believe them yourself. Learning about the negative social roles and stereotypes that our societies place on people who use AAC will help you realize they aren't true and give you the power to reject them from your life and to encourage potential friends to reject them, too.