



Give me shelter. If only it were that simple. The shelter others provide for you may not be quite what you had in mind. Also, the most ideal shelter at one stage of life is unlikely to serve you at another. Finding a living situation to meet your current and future needs is a complex task requiring lots of information and some serious reflection.

Physical access

Finding a place to live is a challenge for most people. Can I afford it, do I like it, will it serve as a headquarters for my life? Augmented communicators have additional factors to consider.¹ One consideration is accessibility. Physical accessibility may include access for mobility equipment as well as a way to use the bathroom; to get food; and to open, get through and lock the front door of your home. Access also can mean being able to get in and out of bed and call for help. Today, many augmented communicators also require modern wiring so they can access electronic technology.

Access to your world

While a roof over your head is a basic need, shelter today means much more. A physically acces-

Give Me Shelter

sible home is not just a shelter, but a pathway to the occupant's world. A home is not accessible if there is no way to shop, work, go to church, visit with friends, take classes, hear music or hang out. Location can make a big difference in a home's accessibility.

Lifestyle issues also are crucial factors in choosing a home. Some people select a shelter on a mountain top because they crave peace and solitude. Others may find a home inaccessible unless it is in a busy neighborhood with good sidewalks and a nearby system of public transportation. To select a truly accessible home, you have to reflect upon which pathways to the world are integral to who you are.

Access to friends

Accessibility also means that people who are important to you can visit you. The finest home is no more than a prison if your best friends can't visit. Will your old friends be comfortable visiting you in your prospective home? Can you see opportunities for making new friends?

Accessible attitudes

Another kind of accessibility is attitudinal. How friendly are the people? If they are not accepting of you, can you win them over? If not, will you be able to ignore them? People's attitudes can make your life a constant struggle, so be sure to think of the kinds of people you may encounter: shopkeepers, neighbors, landlords, orderlies, bus drivers,

INSIDE THIS ISSUE	
Give Me Shelter	
AAC and Housing Issues by Randy Kitch	
ACETS for Work An AAC-RERC Report	
Living Independently by Fiona Givens	
Alternative Housing by Graham Clarke	

Message from the editor

It was the best of highs. It was the worst of terrors. I was elated. I was depressed. I smiled with joy. I cried with sorrow. I knew everything. I knew nothing. What caused these extreme swings of emotion? Moving out on my own.

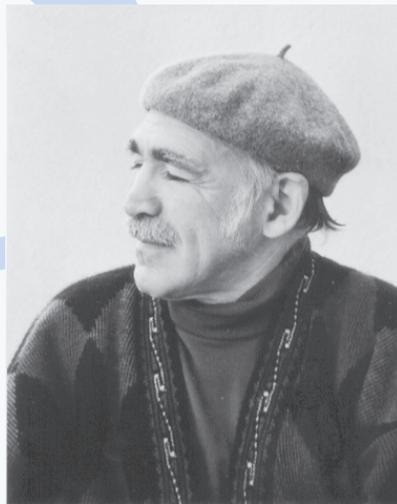
Getting that first place is a milestone in anyone's life, but for me it was a major life accomplishment, comparable to Lindbergh's solo crossing of the Atlantic in an airplane or Edmund Hillary's climb to the top of Everest.

I moved into that first place of mine in the summer of 1967. Finding the place was difficult enough. Potential landlords would take a gander at me and assume the worst. "How is he going to ... ?" You fill in the blank. Most of the questions I was asked at that time would be quite illegal to ask today. I tap danced around issues, fudged the truth and generally made things up. Finally, I found someone who'd rent me a place. She was mainly interested in filling her units with paying renters; outward appearances mattered little to her.

Moving into that first place presented me with unprecedented

opportunities for freedom. Not being under the watchful eyes of my parents meant I could pretty much do as I pleased, like staying up till five in the morning and sleeping till two or three in the afternoon. However, I soon discovered I also had responsibilities. I had bills to pay, shopping to do, and a myriad of other things that needed doing to keep mind, body and soul together.

Living independently in the community is a lifetime adventure. I certainly wouldn't make the same choices today that I did in 1967. The wisdom of age leaches out the foolishness of youth, but to not undertake the adventure is the ultimate foolishness.



personal care assistants, social workers, home staff, employers, family or roommates. Here again, you must reflect to determine whether you can manage any attitudinal barriers you may discover.

Independence

Another consideration is personal control. Living independently means having control over your life activities. Some augmented communicators are not legally in charge of their finances or life's "big decisions." Others are involved in disability programs that take over some areas of control. Also augmented communicators often have family, friends and service providers who want to help make any big decisions.

Balancing the requirements of those who care for you with your own needs and wants can be very challenging. A guarantee that someone will pull you out of bed in the morning undoubtedly means you will give up some control. The desire for safety, affordability, quality, accessibility or supports often results in an uncomfortable collaboration with government agencies whose representatives then have some control over your home.

Even the decision to share a home with personal care assistants, roommates or family members necessitates a balance between control and cooperation. This balance point is different for each person. One person will feel safe and cared for while another feels stifled and restricted in the same home. Again, reflect, reflect to discover what is best for you.

ALTERNATIVELY SPEAKING (ISSN 1075-3982) is published quarterly by Augmentative Communication, Inc., 1 Surf Way, Suite 237, Monterey, CA 93940. Telephone: (408) 649-3050. FAX: (408) 646-5428. One Year Subscriptions: By personal check U.S. & Canada=\$32 U.S.; Overseas=\$40 U.S.; Institutions: U.S. & Canada=\$48 U.S.; Overseas=\$57 U.S. Single Issues \$13. Special rates for consumers and full-time students. Second-Class Postage Paid at Monterey, CA. POSTMASTER: Send address changes to ALTERNATIVELY SPEAKING, c/o Augmentative Communication, Inc. 1 Surf Way, Suite 237, Monterey, CA 93940-3451.

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Politics

Political decisions often determine what kinds of housing arrangements are available in a community. Local governments strive to ensure that there are suitable places for people with disabilities to live. Sometimes politicians make decisions based on convenience and tight budgets; occasionally the decisions are based on a well thought-out social policy. Because local planners implement national programs in their own way, housing and “beds” with the same label can be very different experiences in different communities. If nothing is holding you to your current community, you may wish to research the opportunities in other towns.

If you want to stay where you are because you have developed a network of supports in the community, or if you are involved with agencies who care for the disabled, you may be limited in your choices for shelter. Even so, by thinking about your home as a pathway to the world, you can make subtle decisions which will make a big difference in your satisfaction with your shelter.

Barriers

The following barriers can impede augmented communicators in search of a home:

- Lack of easily accessible information about housing options.
- Lack of funding for affordable housing.
- Red tape, lengthy paperwork, slow processing time.
- Limited availability of affordable housing and residential placements.

- Lengthy waiting lists.
- Financial disincentives.
- Attitudinal barriers.
- Severe housing shortages.

Local supports

Here are some kinds of local agencies which may help an augmented communicator find a good place to live.

- Local housing authorities
- Housing organizations
- Religious organizations
- Local charities
- Home ownership programs
- Independent living centers
- Disability organizations

In Conclusion

Choosing a place to live can be a very time-consuming, emotional, and complicated process. Traditionally, people with severe communication disabilities have not had much of a say in choosing their home. Housing decisions rarely satisfy everyone involved because people have different needs and priorities.

Any effort you make to participate in this process may increase your independence and ultimate satisfaction. You are the one who must decide what will give you the best quality of life. You may have to compromise and adapt, but if you seek out the information you need and reflect on what is important in your life, you just might find a home that is more than a shelter – Your home can be a headquarters for your life!



***Making Decisions
about Housing¹***

Many factors are taken into consideration when choosing a place to live. Remember, what one individual may see as an advantage, another may see as a disadvantage. Here are a few of the many factors to consider in the decision-making process. You may notice that these categories overlap somewhat since they are highly interrelated. A more complete discussion of these factors is available on the ACI webpage at www.augcominc.com in the “What’s New” section.

- Cost
- Lifestyle preferences
- Quality of living
- Safety
- Availability of supports
- Services
- Location
- Accessibility
- Term
- People
- Integration
- Family
- Personal control

Thanks to Suzanne Mellott for providing the research and many of the ideas for these articles as part of her graduate studies.

AAC and Housing Issues

By Randy Kitch



Everyone dreams of a home of their own, whether it's renting an apartment, buying a house or sharing a space with friends. As an AAC user, I have found that communicating independently, building a relationship with my landlord, apartment manager or realtor, and knowing how to manage personal assistants (PAs) are critical to maintaining a home of my own.

Communication

The ability to communicate is essential to obtain the attention and respect of a potential landlord. When I was a renter, I found that most prospective landlords automatically formed an initial negative judgement about me. I would force the landlord to interact directly with me. After about five minutes, he or she would begin to feel comfortable, and his or her attitudes would change about my knowledge of what I needed in an apartment.

Resolving problems

I maintained a good relationship with my landlords by communicating any problems to them directly. I did not want my PAs to negotiate for me, though at times they wanted to. I was responsible for the apartment, and I needed to show that to the landlord. A good relationship came down to one key factor—communication. Once the landlord got used to my AAC device, I was just like anyone else in the apartment complex.

Buying a home

My wife, Brenda, and I decided to buy a house in 1996. We found a realtor, but I wasn't assertive. The realtor mainly talked to Brenda. The realtor didn't know what to think of me. We looked at houses, but the realtor didn't really know what "accessible" was until we came to a house with a step or two, then it hit her—I needed to get into the house to see it.

The realtor and I finally communicated. Brenda and I didn't get the first house we wanted, but now the realtor knew what we were looking for. She found us a house with no steps. The real barriers were my not being assertive enough at the beginning and her attitude, or lack of awareness of persons with disabilities who use AAC.

Personal assistants

Personal assistants (PAs) are indispensable to living in my own home. Hiring personal assistants is no problem because I have prepared a typed job description, a daily schedule, a contract and list of pay days. I pre-program my AAC device with some pertinent questions. Having an AAC device is actually an asset, because it quickly screens out those who don't want the job. How? They don't listen. It is easy to see I don't want them for my PA. Those who do want the job listen well and understand my expectations. The important thing to remember is that personal assis-

tants are my employees and I am their employer. I don't need a caregiver or a nurse.

I control my own life and make my own decisions. However, I'm married to Brenda, so I want to consider my wife's feelings when hiring and training a new PA. It's Brenda's home also. We don't want just any stranger in our home. We both want someone we know and trust. Thus, we both interview the applicants. I ask most of the questions because I will be the boss and will train the person we select.

To sum up, I have these suggestions for AAC users who are looking for housing:

- Meet with a prospective landlord or apartment manager directly and alone to establish communication using your AAC device from the beginning. Be your own self-advocate and take control of your life, before someone else does.
- Establish a good relationship with your landlord or apartment manager by communicating directly to him/her, being responsible for your own place, and following the rules of your lease.
- Train your own PAs, develop a job description, a daily schedule, a contract, have pay days, and be sure they know you are the employer.
- Enjoy living in your own place.

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ACETS for Work!

ACETS is an employment-training program specifically designed for augmented communicators. ACETS (pronounced “Assets”) stands for Augmentative Communication Employment Training and Supports. It is a research project of the AAC-RERC conducted at Temple University and is funded by the NIDRR. The goal is to begin to address the employment obstacles faced by many augmented communicators.

ACETS is a 10-day intensive training program with one year of follow-up services and supports from staff at the Institute on Disabilities/UAP, as well as partners from the business community. ACETS takes place in a “state of the art” technology building on Temple University’s main campus in Philadelphia.

ACETS is designed to teach skills directly related to employment. All applicants must demonstrate a desire and commitment to obtain full- or part-time employment in established public or private companies or to become self-employed. They also must have some idea of what type of job they would like to obtain and demonstrate technical skills using their augmentative communication systems and computers.

To date, most participants have expressed an interest in jobs that, directly or indirectly, require Internet skills. Therefore, the technical component of training focuses on sharpening each participant’s Internet skills, particularly in the areas of information technology and e-commerce.

Training also focuses on skills necessary to obtain and maintain employment including an understanding of:

- Vocational rehabilitation
- Social Security benefits
- Financial planning
- Personal finances
- Work incentives
- Job etiquette
- Disability management
- Resumes
- Interviewing
- Job searching
- Networking
- Managing Personal Assistants
- Use of job coaches
- Small business planning

The ACETS research team is addressing these questions:

- 1: Prior to enrolling in ACETS, what computer/telecommunication skills, employment-related vocabulary, small business planning skills, job-seeking skills, and job readiness skills do competent augmentative communication users have?
- 2: Do ACETS graduates increase these skills? To what extent and how?

3: Do ACETS graduates increase their full-time and part-time employment?

4: What online technology is useful in providing follow up services and job coaching to ACETS participants?

Six augmented communicators from Pennsylvania, New Jersey and California completed the first year of ACETS. All now have clear employment plans, three have part-time jobs and two have started their own businesses. All have updated resumes and web pages.

The second group of ACETS participants completed their intensive training in October 2000. These individuals report being actively engaged in career and business development planning. They are receiving feedback via online coaching and reporting.

For more information, go to www.aac-lerc.com or contact Kevin Cohen at 215-204-1356 or at Temple University, Institute on Disabilities/UAP, Ritter Annex, 4th Floor, Philadelphia PA 19122

The AAC-RERC section is partially funded by the National Institute on Disability and Rehabilitation Research under grant number H133E9 0026. The opinions are those of the grantee and do not necessarily reflect those of the U.S. Department of Education. Published May 2001.

Living Independently in New South Wales

by Fiona Givens

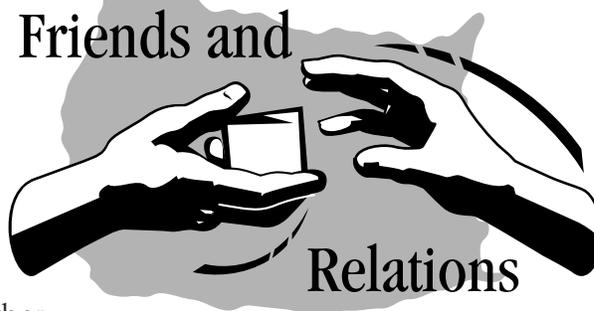
Housing is an extremely difficult issue for people with disabilities, especially AAC users.

In February 2000, I moved out of my parents' home into an apartment by myself subsidized by the New South Wales State Government. The Department of Housing was doubtful about my abilities to live by myself. They asked me really silly questions such as, "Who will cook for you?" In fact, I'm pretty sure they addressed that question to my mother. I found this really offensive because they were implying that I had not thought about the consequences of living by myself. They also insisted on getting reports from third parties regarding my capabilities. I asked my occupational therapist whether she knew of any other clients who had been asked these kinds of questions, and she was not aware of any. I'm pretty sure the Department of Housing did this because I have a severe communication impairment, but I will never know.

I receive government subsidized home care, one and a half hours in the morning for breakfast and showering and one hour at night for dinner, as well as two hours a week for housework and shopping.

I wanted to live by myself because I do not believe in group homes. They are not "normal" environments. You are restricted by the other residents and staff. There is very limited privacy.

The main reason for moving out at this point was that I wanted to do it before my parents got to the stage where they could not look after me. My main concern was that I would end up in a nursing home or something similar. This is probably a bigger concern



for AAC users because it is harder for us to articulate our abilities.

Overall, the move has been successful. However, I do experience a number of difficulties related to being an AAC user. Some of my personal care attendants find me hard to care for because it takes longer for me to tell them what I want. I have also had some negative reactions from some of my neighbors, which has been a bit of a surprise. Some older neighbors ask questions like, "Has the Home Care lady

been lately?" which I find really offensive. There's another lady with cerebral palsy who lives in our complex, but does not have a severe communication impairment. People seem to be more tolerant of her.

I am not an advocate of respite care for a number of reasons. However, I do feel it is important that people with disabilities, especially AAC users, get used to being cared for by people other than their parents. I say this not so much to relieve the parents, although this is a spin-off effect, but to give their child more options. For instance, I lived in Canada as an exchange student for a semester. I could not have gone on exchange if I were totally dependent on my parents. My mother could not have left my father and brother for six months to live in Canada with me. Being able and willing to live apart from my family and hire personal care attendants gave me the option to go on exchange.

People must start planning their future as soon as possible. Children should start developing skills that make them independent, and parents should let their children think for themselves. There is absolutely no reason why AAC users should not expect to live fully independent lives.

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ALTERNATIVE HOUSING FOR AUGMENTATIVE COMMUNICATORS

by Graham Clarke



Personally, I find an institution, at the age of 42 to be somewhat restricting. However, I feel that institutions do have their place, particularly in that transition period between home/school and moving out on your own. These institutions should be relatively small, catering for between ten to fifteen residents. I'd even go so far as to say that a home catering for a specific "sector" of the disabled community would be far more preferable. This streamlining would give the caregivers more understanding of the specific disability. Visiting therapists could visit more clients at one go instead of driving all around the city to see their clients in different locations.

Rubbing shoulders with people with more or less the same disability creates a bond and a sense of belonging. In such an institution, mentoring could be of paramount importance to the future of younger or newly disabled people. Ideally, an older, similarly disabled person could actually run the institution. Doing so would result in a far more compassionate staff to take care of the home's residents.

The way in which institutions are run and managed certainly has an impact on how the residents see life in general. We all know that an institutional environment takes away independence. Residents

are usually not encouraged to get off their behinds and do something worthwhile. Eventually they become "pawns" of institutionalized living. Few seem able to rise above the prevalent suppression, or even oppression, that pervades the building. However, should you find that institutionalized living is the only, or the best, alternative for you, take the following perspective into account.

In my eyes, what a disabled person experiences in everyday life and how the person interacts with their attendants/carers is far more important than the buildings, room sizes, transport and proximity to amenities such as banks, shops and movie theaters. Carers have an enormous influence on the quality of an augmented communicator's life. There's nothing worse than a cold, emotionless approach from a caregiver. Carers gain our respect when they respect us and are willing to help. A dedicated, relaxed-yet-confident approach, efficiency, maturity, honesty, openness and, most of all, love, patience and respect go a long way toward counterbalancing the augmented communicator's daily frustrations and stresses.

Let's face it, augmented communicators can be difficult at times. Our frustrations can build up inside and be exacerbated by

being unable to talk and having to communicate relatively slowly. New attendants should understand that frustration is not necessarily directed at them.

It is imperative that carers and people with disabilities form relationships based on patience and respect. This is, however, easier written than accomplished. In fact, it is a bit idealistic. While I realize this is so, I also feel that it is possible to attain such qualities in the carer/disabled individual's relationship. Respect gains respect. Patience is paramount.

I believe that we ought to take an interest in our carer's well-being, their family, their moods, etc., so that the carer/patient scenario becomes more of a person-to-person relationship. Of course, just as you take an interest in them, they should take an interest in you as a person. You both can benefit from the relationship.

An institution can be a good place to live if the people running and managing an institution encourage patience and respect from everyone, prudently select the caring staff, and are aware of and sympathetic toward the augmented communicator's needs.

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Sources & Resources

1. Suzanne Mellott provided the research and many ideas for the articles about housing options for augmentative communicators as part of her graduate studies at Pennsylvania State University.

2. Suzanne Mellott compiled these Web resources. Her full list of Web resources about housing options for augmentative communicators is available on the ACI website at www.augcominc.com

Web Resources for Accessible Housing

While local decisions determine the kinds of shelter which you will find in your community, national policy affects the future. There are housing nondiscrimination laws such as the Fair Housing Act in the USA. Some people with disabilities have organized on the national level to promote social change in housing for people with disabilities. American Disabled for Attendant Programs Today (ADAPT) in the USA is working to ensure that no one is forced to live in a nursing home. The international Concrete Change organization works to make all homes “visitable.” Here is a list of some of the wide variety of websites which include information about housing, access and disability.² If you are not happy with your choices for shelter, consider working with an organization to create change.

<http://www.design.ncsu.edu/cud/>

The Center for Universal Design is a United States research, information, and technical assistance center that evaluates, develops, and promotes universal design in housing, public and commercial facilities, and related products. Lots of resources here.

<http://concretechange.home.mindspring.com/>

Concrete Change. An international effort to make all homes visitable. Site is based in the USA.

www.abledata.com/text2/icg_hous.htm

This section of ABLEDATA includes information on accessible housing, the Fair Housing Act, and ways to achieve accessible housing. The Informed Consumer’s Guide to Accessible Housing is also on this site.

<http://www.abilitycenter.org/Core/housingservices.html>

The Ability Center of Greater Toledo is an independent living center which assists people with disabilities in obtaining affordable and accessible housing in the greater Toledo, Ohio area. This is a prime example of a community providing the information people need to find housing. This site includes some great links.

<http://soeweb.syr.edu/thechp/houser.es.htm>

This is a collection of resource materials on housing for people with disabilities. This site is slightly older, but it is a great site for information regarding home ownership. Most of the resources come from the USA.

<http://www.after16.org.uk/text/pages/house.html>

Housing: A place to live. This is an excellent site for individuals who are only beginning the selection process. This site details

every housing option in the UK and provides some pros/cons.

<http://www.hud.gov/fhe/fheact.html>

Fair Housing Act homepage. Detailed descriptions of each section of the United States Fair Housing Act in understandable terms.

<http://www.thistle.org.uk/links.htm#Accessibility%20links>

The Thistle Foundation is a long-time provider of institutional living for people with disabilities in Scotland. They are progressing beyond institutional care into an all-encompassing approach which treats everybody as an individual and develops services to meet their needs. Their links include a great index of disability housing websites. Communication aids and housing resources are listed together under the heading “accessibility.” A bit hard to find but worth the effort.

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