



## Community, Support and AAC

by Tracy Rackensperger

All individuals need the support of others in their lives. People rely on family, friends, co-workers and professionals for support through difficult times and to share in special moments. Individuals rely on others for companionship and love, as well as expertise and advice. This issue of *Alternatively Speaking* spotlights the unique kinds of daily and occasional supports people who rely on augmentative communication use in their lives. These supports include work by those who are paid to provide support and the assistance volunteered by friends, family and acquaintances.

Someone who relies on AAC may benefit from assistance with grocery shopping. Someone else may use assistance with remembering tasks. Many people have others help them maintain their AAC system. Whether it's driving to the store, providing reminders about tasks, taking care of equipment or helping with eating and bathing, the variety of supports needed is unique to each individual. Each must decide who is going to provide the needed supports.


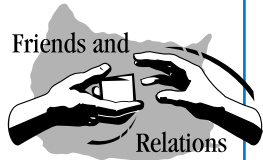



Individuals usually (but not always) rely on two kinds of support. Natural supports are “any assistance, relationships or interactions that allow a person to

secure, maintain and advance in the community of his/her choosing in ways that correspond to the typical routines and social actions of other people and that enhance the individual’s relationships.”<sup>1</sup> Depending on the size and configuration of a person’s social network, the availability of natural supports can vary.

Paid supports are services that have a cost. These supports are often paid for by the government or a third party and are limited in the amounts, times and places where they are available.<sup>2</sup> They may be provided in the person’s home, elsewhere in the community or in designated special care settings. For example, someone who needs assistance at dinnertime everyday may arrange for that support in her home.

### Social Role Factors

Healthy relationships involve mutual respect and reliance on one another. When I spoke with peers who have communication disabilities, they reported the importance of keeping the social roles of friends, family and others as typical as possible. They take

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# Message from the author

**M**y life has changed dramatically over the past few years. Prior to 2005, I was living in my parents' home and was totally dependent on them for my physical and financial support. When I moved out of their house, became employed in an office setting, and began to have increased opportunities to develop personal relationships, my whole life changed. My family no longer could be the sole providers of support for me. Also, I needed to expand my support network so I could be more independent.

So the challenge began. How should I balance the support for my personal care among family, friends, volunteers and paid individuals? Well, I still haven't quite found the answer to this question. In fact, asking myself this question has led me to ask even more questions, such as, "What are the proper roles of individuals who support others in life?" and "What configurations of support systems are effective for people who use augmentative communication?"

Most people who rely on augmentative communication need a great amount of support to be able to live and be productive. However, we are all individuals

and, as such, need different types of supports that enable us to participate actively in our communities. Being able to live among our peers and exercise the right to make our choices, as well as having opportunities to learn and love is what makes life worth living. In turn, taking responsibility for managing our own supports enables us to live in the community the way we want and allows us to control our future.

This issue of *Alternatively Speaking* does not provide a "best" answer about how to balance supports. Because everyone is unique, there is no best way to organize a system of supports. In fact, I believe each of us will find our own distinctive way to manage supports. I hope the thoughts and perspectives contained in this issue may provide some guidance. **A**



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care not to ask too much of their natural supports or take advantage of these important relationships. Thus, in deciding how to utilize natural and paid assistance, they try to keep the line between friendship and professional service clear. Also, they noted that particular difficulties may arise when they hire friends as personal assistants. They do not expect their friends to provide support services when they are "off-the-clock."

## **Economic Factors**

Ideally, individuals who rely on AAC should have access to both paid and natural supports. Reliance on paid assistance, however, is often rather expensive. Some individuals can afford to pay for personal assistance. Some have health insurance or employer support. Most will rely on government funded programs. Assistance supplied by the government depends on eligibility and thus can change depending on a person's economic factors and the political climate. Individuals who make a modest living may not be eligible for any assistance. Often, family and friends are a part of an individual's support system, not only for social reasons, but for economic ones as well.

## **The Balancing Act**

Balancing supports is a complicated, ever-changing and lifelong process. It is a personal journey that reflects each individual's social, financial and emotional resources, preferences and values. **A**

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# On the Balance

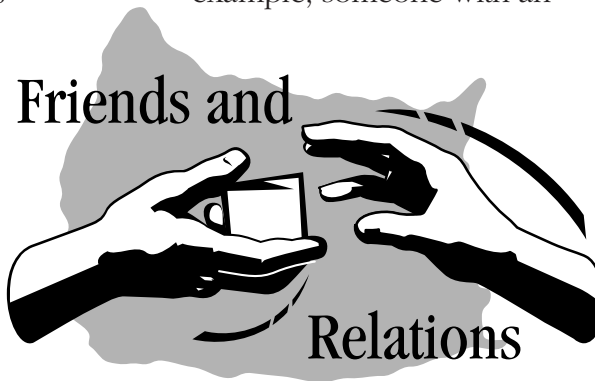
by Tracy Rackensperger

**B**alancing paid and natural supports is a challenging endeavor for individuals who rely on AAC. The factors influencing decisions about how to juggle the kinds of supports someone needs are unique to each individual's circumstances and preferences. Each person will have his or her own thoughts about how to organize a system of supports because he or she will have different needs, desires and circumstances. Thus, no two individuals' support systems will be identical. Furthermore, it is highly unlikely that anyone's support system will remain the same over time. This article highlights one possible approach to managing a system of supports that can work well for an individual who relies on AAC. It is based on the Circles of Support, a concept that began in Canada and has spread internationally.<sup>3</sup> This concept is used in person-centered planning and is frequently applied within the developmental disabilities communities.<sup>4</sup>

## Circles of Support

"The Circle is hard to describe; it's too simple."<sup>5</sup> Recently, I had an opportunity to attend a training conducted by the internationally-known Jack Pearpoint and Lynda Kahn about some tools and concepts used in person-centered planning.<sup>6</sup> They pointed out that

proactively developing and using Circles of Support allows an individual the opportunity to identify and take charge of the types of assistance he or she chooses to use every day. For example, someone with an



acquired disability might find identifying Circles of Support useful as she adjusts to life as a person with a disability, while a high school student with developmental disabilities may use Circles of Support to ease his transition to adult services.

To start the process of using Circles of Support to assist in the management of supports, the individual invites his or her friends and family members to meet and discuss needs and concerns. Together, they spend time developing a comprehensive plan for support during specific activities. The resulting plan is consistent with the individual's life goals and dreams.

Individuals can decide to use this process in any environment, such

as a family home, individual home, group residence, work setting or school. Utilizing Circles of Support can help open up discussions about what needs to get done every day, as well as what supports (strategies, technologies and people) are required to make it all happen. The process can help clarify the roles of family members, friends and paid individuals and help individuals figure out ways to develop a workable support system. In addition, these discussions can provide opportunities for loved ones to express their perspectives and consider the types of support they might provide now and in the future. From these planning sessions, individuals who rely on AAC can put into action a workable system for balancing paid and natural supports.

## Personal Reflections

When I first moved out of my parent's house, I did not go through this process. At the time, my parents were still providing my support, but the lines of communication between paid support workers, family members and friends weren't working. Currently, I am living on my own. I continue to struggle to achieve a balance of supports that gives me the greatest amount of control over my life.

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## *A System of Supports*

With support to get transportation, I can work, shop, date and go to the movies.

With support to work, I can be around interesting people, earn money and do something I enjoy.

With support to maintain my assistive technology, I can use an electric wheelchair, communicate using a speech generating device and access a computer.

With support to handle emergency situations, I can live independently and feel safe and secure.

With support to deal with medical personnel, I can be proactive about my healthcare, get medical information and get help when I am sick.

With support to have sex, I can have a partner, have intimate relationships and enjoy my body.

With support to travel, I can attend conferences, see my far-flung friends and colleagues, learn new information and enjoy a variety of vacation experiences.

With support to shower, shave, toilet and dress, I can be healthy, hygienic and ready to go.

With support to eat and drink, I can get proper nutrition, stay healthy and engage in social eating and drinking.

With support to pay bills, I can take financial responsibility and maintain a budget.

With support to have privacy, I can make personal decisions and take informed risks.



**I** knew the day would come when I would have to manage my own supports because I have always had dreams of moving into my own place, having a career and living independently in the community. Knowing this, it would have made sense for me to plan ahead and work out how exactly I would accomplish everything I planned to do. Yet, due to my laid-back nature and my notion that everything eventually comes out okay in the end, I conducted very little pre-planning. Thus, until I was 27 years old, my parents were the sole providers of the physical support I require each day.

### **You're hired!**

It was late May 2005 when I received that life-changing call from the University of Georgia. The person who was on the phone requested that I interview for a position at the Institute on Human Development and Disability. It had been approximately a year since I graduated with a Masters degree from my local university in Orlando, Florida, and I had been looking for jobs all over the Southeast. In June, I

# Learning Through Trial and Error

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was interviewed at the University of Georgia and then hired. They gave me a little over a month to find a place to live and move my belongings to Georgia.

Given the timing, my family decided to move with me until I could find paid supports and other means of assistance to enable me to live in my new apartment. For the first months, however, my mother would help me while we figured things out.

Because I have a full-time job, I did not (and still do not) qualify for government funding for personal care assistance. Nor can I afford to pay directly for all the support I require. My plan was to offer a college student free rent and utilities in exchange for providing basic physical assistance three times a day, for about an hour at a time. Then, I would pay someone for assistance a few days a week for things like shopping for groceries.

## Apartment living

Well, the apartment living situation was a disaster. I waited way too long to advertise for a roommate and to garner additional

support. Additionally, a member of my family suffered a severe medical crisis. The only solution at that time was to move back in with my family.

In the meantime, I found that the process of building natural supports and relying on them was challenging for me. I grew up in a very conservative family, where the ideas of self-reliance and independence were instilled. Sure, it was okay to ask friends to help with small tasks, such as pouring a drink everyday at lunch, but I didn't ask them for major assistance like driving my van. I still value these concepts; however, friends kept offering to do things for me, and gradually I have learned to use natural supports more regularly. I have friends who I know I can call upon for assistance in the same way they can ask me for assistance.

## First time home owner

I bought a house in June 2006. This time, I wasted no time in advertising for a roommate. Family members were still dealing with a major medical situation

and unable to support me as they had in the past. In August, I found a roommate. In October, a volunteer from a program run by my department began to assist me with shopping. Everything was great for several months.

However, when my roommate left in December 2006, I only had my volunteer and friends to assist me, so I temporarily moved back home for two months while I looked for a new roommate to be my major support person. In February, I returned to my house having found a new roommate.

## Is everything perfect?

No, but it's working adequately. I now know that managing the supports I need to live is a challenging and long-term process. I know I have to plan ahead and have contingencies. I need to be prepared for the "what ifs." I'm still learning how to integrate natural and paid supports in my life. I am inspired to continue to try new approaches to piece together the assistance I need to live my life.

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# The Journey

by Tracy Rackensperger



**I**magine being a person with complex communication needs living in California in the 1960s and 1970s. These volatile decades would ignite a variety of social change movements, including the disability rights movement. Thanks to many legendary leaders, such as Ed Roberts, the Disability Rights Movement would expand and, eventually, empower millions of people with disabilities to advocate for freedom, rights and equality.

Imagine reporting on the push for the passage of what is now called the Rehabilitation Act of 1973, mandating federally funded programs and buildings to become more accessible in the U.S.A. Since conventional methods of getting laws passed had not been effective, sit-ins at federal buildings and other forms of protests were being organized throughout the U.S.A.

The founder and editor of *Alternately Speaking*, our own Michael B. Williams, lived in the hub of this time of social change and was an active participant in the early Disability Rights Movement. He converses about these experiences and more in *How Far We've Come, How Far We've Got to Go: Tales from the Trenches*, a presentation in [The AAC-RERC Webcast Series](#), now available for viewing online. (To order a DVD copy, contact Augmentative Communication, Inc. at 831-649-3050.)

Michael reflects on his adventures as a young man who became politically involved in a changing society. Michael documents his life and personal understandings of the history of the Disability Rights Movement. He also gives insights from the perspective of someone whose speech is difficult to understand about the days before AAC.

From Michael's youthful optimism to his ground floor involvement in the birth of the field of augmentative communication, Michael's talk is about pathways to achieving independence. *Tales from the Trenches* will help you reflect on your own journey and place in the Disability Rights Movement, which continues to enable more and more individuals worldwide to manage their own lives and further their independence.

If you're a young adult who relies on AAC, you'll see that some things haven't changed even though many barriers have fallen. As a family member, you'll be able to think about how best to support your child's goals and dreams. Professionals can use this AAC-RERC webcast or the DVD in their presentations. All can learn about some important disability history and the personal journey of one of the great leaders in AAC. It is, after all, through the lives of people who use augmentative communication that we can see the benefits of today's changes in policies and practices. We've come a long way, thanks to people like Michael B. Williams, and we must keep on fighting for freedom, rights and equality!

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## The AAC-RERC Webcast Series at [www.AAC-RERC.com](http://www.AAC-RERC.com)

- *Maximizing the Literacy Skills of Individuals who Require AAC* by Janice Light
- *How Far We've Come, How Far We've Got to Go: Tales from the Trenches* by Michael B. Williams
- *AAC: A User's Perspective* by Colin Portnuff
- *AAC for Aphasia: A Review of Visual Scenes Display Project* by David Beukelman
- *AAC Interventions to Maximize Language Development for Young Children* by Janice Light
- *Overview of the Health-based Funding Programs that Cover SGDs* by Lew Golinker
- *Supporting Transitions to the Adult World for Individuals who use AAC* by David McNaughton



# Transitions to Independence

by Tracy Rackensperger

**T**ransitions are a part of everyone's life. Life continually changes, and all individuals have to adapt. One of the biggest transitions for young adults is going from high school to independent living, post-secondary education and/or employment. For those of us who use AAC, a successful transition often requires the support of family, friends, the high school, community service organizations, personal care assistants, classroom aides and many others.

David McNaughton, who teaches at Pennsylvania State University, and his colleagues conducted research to identify supports that are important to successful transitions for individuals who rely on AAC.<sup>7,8</sup> The project, which was funded in part by the AAC-RERC, has identified major stumbling blocks to transitions, as well as important supports needed for successful transitions, especially in the area of employment. By conducting focus group and case study research involving people who rely on augmentative communication, Dr. McNaughton has documented successful strategies that assist in ensuring positive results.

How an individual perceives his or her quality of life is one important factor in defining successful

transitions. Different issues are important to different people: While some individuals will place a strong emphasis on the opportunity to live independently, other individuals may focus on maintaining close family ties.

For some, employment is an important transition goal. These researchers found that individuals who rely on AAC have more opportunities for employment if they receive a high level of formal education, enjoy a large and well-developed social network and have support from individuals who have high expectations for them. Being highly literate also is an important factor in finding employment, especially for those with more significant disabilities.<sup>9</sup> In turn, poor educational services, limited social networks and low expectations for achievement are barriers to making a successful transition into employment. Additionally, society's lack of knowledge and limited experiences with individuals who rely on AAC are frequently reported as challenges to employment.

Therefore, it is very important for family members, friends, teachers, AAC clinicians and others to actively support the transitions of individuals who rely on AAC. Family members can assist in

meeting new people and maintaining ties to the community. Friends can help individuals vocalize their goals and dreams. Educational personnel can empower individuals by teaching personal responsibility at an early age. And AAC clinicians can help to make sure that AAC systems meet the current and future communication needs of each individual.

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A webcast summarizing this research, *Supporting Transitions to the Adult World for Individuals who use AAC* by David McNaughton, is available as one of the titles in [The AAC-RERC Webcast Series](#). To learn more about the AAC-RERC, watch the AAC-RERC Webcast Series or monitor the projects, visit [www.aac-lerc.com](http://www.aac-lerc.com).

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## Message from the editor

**T**racy Rackensperger is the guest author for this issue of *Alternatively Speaking*. We are honored to have her participate in our work here at *AS*. The strong, clear voices of individuals who rely on AAC push the field of AAC forward. Tracy has one of these voices. Please welcome her as you read her thoughts on managing supports for independent living.

Tracy's articles remind me of the entertaining television movie, *Door to Door*, starring William H. Macy. It tells the story of Bill Porter, a real-life salesman with cerebral palsy. We watch Bill use persistence and guile to build a

system of supports that allow him to achieve his goals of independent living and employment.

Earning enough money to finance one's own life is difficult; adding in the expense of personal care assistants at home and assistants at work is a significant extra economic demand. However, the pressure is not just financial. As Tracy so well describes, managing a staff to assist in independent living is literally a second job.

*Door to Door* can be found on DVD and video at many libraries and video stores. You may want to watch this movie after reading Tracy's articles. It is sure to give

you further food for thought about possible ways to create supports for your own life's journey.

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