

Coping with the End of Third-Party Reimbursement for Individual Speech-Language Pathology Services

Unfortunately, the NAA continues to receive requests for help from families who feel that their third-party reimbursement for speech-language therapy has been ended long before the potential for recovery of communication skills had been reached. It is a fact that third-party reimbursement is paying for fewer healthcare services and for shorter periods of treatment. Although persons with aphasia can continue to acquire communication skills for decades, third-party reimbursement for speech-language therapy is usually available only for the first few months after a person acquires aphasia.

The NAA sought to explore the alternatives open to families at the end of third-party reimbursement for speech-language pathology services. We thank the three speech-language pathologists who responded to NAA's appeal to discuss ways for families to cope. Each of the three participants in the conversation which follows have treated hundreds of clients with aphasia, trained student clinicians, conducted research and contributed to textbooks and/or journals on the topic of aphasia. They include **Jackie Hinckley**, Associate Professor, Communication Sciences & Disorders, University of South Florida; **Anita Halper**, Speech-Language Pathologist at the Rehabilitation Institute of Chicago, and **Audrey Holland**, Ph.D., who is an Emeritus Faculty member, Department of Speech and Hearing Sciences, at the University of Arizona in Tucson.

What do you tell families when they tell you that they have to end speech therapy treatment because they have no more third party reimbursement?

Holland: I believe it is the responsibility of SLPs to address this issue as early as possible in the rehabilitation process. I see the goal of rehabilitation as helping families and people with aphasia to "Get off to a good start" in their long road to regaining good quality of life. In a sense, all of therapy should be preparation for getting on with the lives that were interrupted by stroke or some other cause of the aphasia. Families and individuals with aphasia need to learn early in the recovery process about the alternatives available in their community such as less expensive clinics who provide training for students, support or more psychosocially oriented programs for aphasia. They also need to be introduced to the resources that are available to them via the Internet, home programming, distance learning, advocacy groups such as the NAA and the always growing literature and personal narratives on coping with aphasia.

Halper: Groups are very important. However, if individuals want to continue in individual therapy, but don't have the financial resources to work one-to-one with a therapist, they can seek out a university-run clinic. Speech-language pathology students need experiences working with adults with aphasia in their training. This often works out well for the client. A licensed speech-language pathologist from the university's faculty supervises student



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clinicians in their preparation and delivery of therapy. Most university clinics have to charge something for their services, but it is usually less than for other individual therapy. There may also be on-going research projects that a person with aphasia can volunteer for. It isn't always the case that participating in a research project is going to help your communication skills, so you need to be clear about the goals of a research project before you get your hopes up.

Hinckley: Unfortunately, I don't think that most families anticipate their next move when the end of their reimbursement for individual therapy is approaching. While you are still receiving services, it's important to be thinking ahead as much as possible. Consumers should ask their therapists the following kinds of questions:

- 1.) About how long do you think I'll be able to receive therapy? What will happen after that?
- 2.) Could you please make sure to provide me with a home program before we get to the end of our therapy? Something that I can keep doing for practice when I'm no longer getting therapy?
- 3.) Do you know of any community resources that will help me after my insurance runs out? University clinics or aphasia community groups?
- 4.) Can you help me find or help me provide education to community volunteers, maybe someone from my church or religious group or other community service organization?

Do you have any tips for individuals who are looking for research projects/clinical trials to participate in?

Holland: For people who live near research hospitals and college and universities, the easiest way is by asking their clinicians about the projects that are going on in their community, or simply to call facilities and ask about them. Programs that do research in aphasia are delighted to find out about individuals who are interested in participating. A cautionary note here is that it is not always possible to find a fit between the problems a person with aphasia might be having and the research that might be underway in the community at any particular time. But bringing your interest to the attention of the researchers is always welcomed by the scientific community.

How can speech pathologists help families prepare for the end of therapy?

Hinckley: The family needs to have an accurate description of what the person with aphasia may be able to do in the future. This description is a critical first step toward three very important ways that the speech-language pathologist can help the family get oriented toward a new life. First, families can anticipate activities they can still share. Person with aphasia should be encouraged to maintain a role in financial and other planning. Think about social and family events, and hobbies that the family can



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share. This collective planning will help families think about how their lives together will change and how it will stay the same. Secondly, the speech-language pathologists should provide the family with specific suggestions for maintaining active and stimulating communication among family members. Whatever methods are appropriate for the person with aphasia should be explored. And third, the family should request recommendations for home practice if the clinician has not already offered these.

Holland: One of the most exciting new developments in our field, it seems to me, is that there is a growing recognition that “the end of therapy” does not really mean “the end of recovery.” “The end of therapy” is simply when the available funding runs out, nothing more, nothing less. In my answer to the first question, I tried to outline some alternatives for ways to continue the recovery process that are not strictly dependent on the clinician’s expertise in helping to restore language and communication abilities. I feel pretty strongly that true clinical expertise also involves helping families and individuals with aphasia to evaluate and choose alternatives to funded therapy that make sense to them, helping them to realize that direct funded therapy is only one of the routes to living a full life despite aphasia. Fritz Perls once said “The end of therapy is when everything becomes therapeutic.” I take this point very seriously.

We have several families that ask us about devices and computer programs after their speech therapy has ended. Do you have any tips or advice?

Hinckley: Certain kinds of computer practice can help to maintain or improve language skills. However, the computer practice needs to be appropriate to the skills and need areas of the person with aphasia. That’s why it is best, if possible, to have a speech-language pathologist who knows you suggest the right kind of computer programs for practice –you do not want to waste money and time on things that are inappropriate or possibly even frustrating. In addition, the computer can provide so much more than just “drill”-type practice. Programs that read the screen out loud can help people who have trouble reading and would like to access internet sources for current events or other interests. Other software programs can help you to find the words you need to write emails and stay in touch with friends or families. You might be able to learn to use software that helps you take back jobs like household finance management, or sending greeting cards to family and friends on special occasions. Also, there might be useful volunteer jobs or even paid positions that would become accessible to persons with aphasia once some computer skills are learned.

Holland: There are a number of computer programs that aphasic individuals find useful for drills and practice, and I think it’s important to explore them for their potential usefulness in specific cases. The same holds true for some of the devices that are available. But I think this is a field that is standing on the cutting edge of some really



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significant breakthroughs, such as the development of virtual clinicians for home use, the use of email, Internet, iPod and Wii interactive technologies, and so forth. I believe it is the responsibility of individuals with aphasia, their families, and above all clinicians to keep up on these advances and for clinicians to offer sound advice to families about what might or might not be useful for particular individuals.

What else should families consider?

Hinckley: It is important to change and adjust focus. The end of third party reimbursement may be a time to shift your focus as a family from medical and therapy back to yourselves as people who are interested in the world and each other. However, aphasia will always be a part of that. An Aphasia Community Group may be a place to receive the support you need to pursue this change of focus. Staying in touch with others is important.

Holland: I tried in the above to include both aphasic people and their families in my previous comments. But I think I should be more specific. To the extent possible, individuals with aphasia must take leadership in the role of management of their own aphasia. Personal responsibility, not just the family or clinician responsibility is important to healthy recovery. One of the best ways to be a useful member of society is to help others. Experienced persons with aphasia can help newer ones by sharing their stories and their experiences. In some places, people who have lived with aphasia for a long time visit with new aphasic ones. They have prepared guidelines for coping that express their unique understanding of aphasia. Some spouse groups provide similar guidelines for family members. People with aphasia and their families can help to educate the healthcare community as well as first responders and shopkeepers about aphasia and why it is important for them to know about it.

Finally, family members must remember that their own health and quality of life is just as important as that of the person who has aphasia. In fact, it is important to the aphasic individual's quality of life, too. It is not just taking care of the person with aphasia; the caregiver has a responsibility to take care of him or herself. ♦