

Starting an Aphasia Center?

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ABSTRACT

Starting an aphasia center can be an enormous challenge. This article provides initial issues to review and consider when deciding whether starting a new organization is right for you. Determining the need for the program in your community, the best size and possible affiliation for the organization, and available resources, as well as developing a business plan, marketing the program, and building awareness in the community, are some of the factors that are discussed. Specific examples related to starting the Aphasia Center of California are provided.

KEYWORDS: Aphasia, aphasia treatment, aphasia center, life participation

Learning Outcomes: As a result of this activity, the reader will be able to (1) describe several ways to determine whether there is a need for an aphasia center in their community, and (2) describe three important resources that are important to consider before starting a new program.

The Aphasia Center of California (ACC) is an independent not-for-profit organization providing speech-language treatment, clinical research, training, and consultative services related to aphasia. The mission of the ACC is to enhance communication skills and maximize psychosocial well-being for all those affected by aphasia following stroke.

We opened our doors 15 years ago after completing a large research project designed to evaluate the efficacy of communication group therapy for people with chronic aphasia. At that time, our research participants ex-

pressed enthusiasm in continued participation in aphasia group programming—we had identified a definite need for expanded aphasia services in our community. We began by offering communication group therapy, but our programming has expanded over the years to include book connection groups that focus on reading and writing,¹ news forum groups, movie groups, an aphasia Internet clinic that supports the self-identified need for Internet use, individual speech-language therapy, a quarterly educational series on stroke, a caregivers group, a “sit and be fit” exercise class as

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well as “club aphasia” for social interaction and games.

Our approach to aphasia has proven both innovative and cost-effective and allows people with aphasia to continue receiving treatment beyond the initial rehabilitation period following stroke.^{2,3} Our research has demonstrated significant gains in both communication and psychosocial functioning after intervention.^{4,5} In fact, many participants in our programs have reentered community life for the first time since the stroke. The positive outcomes and inventive programming has drawn the attention of people affected by aphasia as well as speech-language pathologists interested in new service delivery paradigms.

There are currently 8 independent aphasia centers recognized by the federal government as 501(c)(3) charitable organizations in the United States.⁶ The ACC was the first such organization, founded in 1996. Five years later, in 2001, the Stroke Comeback Center in Virginia began, followed in 2002 by the Aphasia Center of West Texas, and in 2003 by the Triangle Aphasia Project in North Carolina and the Adler Aphasia Center in New Jersey. The remaining Aphasia Centers have started since 2008: the Snyder Center for Aphasia Life Enhancement in Maryland, the Houston Aphasia Recovery Center in Texas, and the Aphasia Community Friendship Center in Michigan. In addition to these independent aphasia centers, the National Aphasia Association Web site currently lists more than 300 aphasia groups and programs that meet on a regular basis in the United States and Canada (<http://www.aphasia.org>). This number has grown dramatically over the past 20 years.*

Since founding the ACC, I have been asked by several speech-language pathologists whether they should start an aphasia center.

My first response is to answer no—starting and sustaining an independent organization requires a significant sacrifice. In my experience, an enormous commitment is required, and the result is many hours of work with less pay than one would receive at another job. However, for the person with a good amount of determination, as well as the right set of life circumstances, starting an aphasia center can be an extremely fulfilling way to meet the needs, and change the lives, of people with aphasia.

WHY DO YOU WANT TO START AN APHASIA CENTER?

Starting an aphasia center requires thoughtful responses to several considerations and questions. The first step is to determine the actual need for the proposed organization. What are the unmet needs for people with aphasia in your community? If their needs are already being met, it is unwise to duplicate services.

We started the ACC because there were no comprehensive aphasia programs or ongoing aphasia groups available to community residents in the Bay Area of Northern California. We knew there was a need because of the fantastic response we had received during participant recruitment for our communication group treatment efficacy study.^{4,5} Because we had documented an unmet need, we moved forward.^{2,3,7}

Although our needs assessment was serendipitous, there are other methods of assessing needs for a program in your locale. Local and regional needs assessments, undertaken by public and private agencies, may be available that can help with your decision making. In addition, it is important to discuss your potential ideas and gather input from people with aphasia, family members affected by aphasia, other agencies working with stroke survivors, potential funders, and local government agencies, before moving forward with your ideas.

SHOULD YOU BECOME AN INDEPENDENT ORGANIZATION?

Before starting the ACC, we considered working under the auspices of another not-for-profit organization. Because we had the advantage of

*The careful reader will note discrepancies between these statistics and those reported in Simmons-Mackie and Holland (this issue). There are many reasons for this, including the fact that centers that report themselves as not-for-profit may derive that status from larger institutions (e.g., hospitals or universities) in which they are housed. Another possible source of discrepancy between the actual numbers of groups and centers may result from different polling strategies used by the National Aphasia Association (NAA) and the Simmons-Mackie and Holland reports.

having created the core of the program (i.e., communication groups) while running the research project, we wanted to be able to continue something very similar. We made the decision to strike out on our own rather than compromise the program components. Fifteen years later, it is hard to say whether that was a wise or unwise decision. There were certainly many personal sacrifices that were necessary to get the organization off the ground. But we believe that there were likely fewer bureaucratic roadblocks that we likely would have encountered, if we had decided to work with another organization.

Large or Small?

One may be able to accomplish similar goals with running a small program versus a large organization. Offering an aphasia group, or even a few groups, under the auspices of a hospital or university, may meet the needs in the community, while also saving the significant time, effort, and/or resources that are needed when creating a large organization. In general, it is more challenging to start and sustain a large program compared with a smaller one.

For-Profit or Not-for-Profit?

If a decision is made to move forward with forming a new organization, one needs to determine if it will be a not-for-profit or a for-profit venture. This is a critical decision as it will have an enormous impact on all fiscal and management issues that follow. A discussion of the pros and cons of for-profit versus not-for-profit organizations is beyond the scope of the present article, but information is available from the Internal Revenue Service, the Small Business Administration, state government publications and Web sites, and numerous business book publishers. The reader is also directed to Nolo Press (<http://www.nolo.com>) for publications that provide helpful step-by-step instructions for starting for-profit and not-for-profit businesses.

Do You Have a Business Plan?

One of the first steps in starting a new organization is to write a business plan. A business

plan states the reasons for starting a business, defines the goals of the business, and lists the specific plans one has to reach those goals. In addition to a business plan, a SWOT (strengths, weaknesses, opportunities, threats) analysis of the proposed organization provides useful information.^{7,8} Taken together, the business plan and the SWOT analysis provide a new organization with a strong foundation and road map for going forward. Answers to the following questions and suggestions should help to complete a business plan and SWOT analysis.

What Are Your Resources?

Money, space, time, and staff are all needed to run an aphasia center. Some independent aphasia centers were started with little or no start-up funding or seed money. This was true of the ACC (<http://www.aphasiacenter.org>) and the Aphasia Institute in Toronto (<http://www.aphasia.ca>). These organizations thrived when they started small and gradually added programs as they found revenue to sustain their expansion. Other independent aphasia centers, such as the Adler Aphasia Center in New Jersey (<http://www.adleraphasiacenter.org>) or Connect in England (<http://www.ukconnect.org>), started with seed money and also a building to house their respective programs. This allowed them to offer a large array of programs from the very start. However, as mentioned above, a danger in being too large is in being able to sustain the organization over time. As revenue ebbs and flows due to several external and internal factors, organizations with big expenses (e.g., staff, rent, insurance, etc.) may find it challenging, or even impossible, to locate new funding needed to keep existing operations going.

Revenue

Finding seed money to start an organization is only the first step. To sustain a healthy organization, ongoing sources of revenue are necessary. These revenue sources should become increasingly diverse, so that the organization isn't adversely impacted if one or more sources are eliminated due to changes in funding or

other factors. When an organization becomes too dependent on a particular donor, grant-making institution, or even a stream of revenue from a particular program, it runs the risk of collapse if that revenue is suddenly withdrawn.

Space

Another very important consideration is to determine the location or space that is available to house the center. Will this program space be donated, rented, or owned? Is the space located near public transportation? Is the entire space wheelchair accessible? Once space issues are determined, one needs to consider the expenses that may or may not be included with that space: utilities, insurance, furniture, treatment materials, and so on. There is often a trade-off among various program sites. One space may look perfect—it is large and modern with beautiful furniture and other amenities. However, the monthly rent is high and the insurance premiums will be significant. Another possible space may be smaller and outdated, but it is donated free of charge and the utilities are included. Depending on the mission of the organization, the current program needs, and the current and projected financial resources, different conclusions may be reached regarding which program space is the right one. The right decision will be the one that provides the “best logistical fit” for that particular organization at that particular point in time.

When starting the ACC, we had the opportunity to continue using the space in the City of Oakland Senior Center where we had conducted our research study. The space was quite small, but it was rent free, allowing us to use more of our donated funds for program expenses. This space will never win an interior design award, but it is accessible, is close to public transportation, is part of a larger bustling urban community, and, with some creative use of space, has met our past and present program needs.

Staffing

Another critical decision to make when starting an aphasia center is one about staffing. Will program staff be speech-language pathologists

or trained volunteers? If speech-language pathologists, will they be full-time, part-time, or per diem? If volunteers, how will they be trained and who will do the training? Will other classes or disciplines be provided by the center? If so, which staff will be responsible for these programs? How much time will you have to devote to the organization? We made the decision to offer speech-language pathologist-facilitated groups based on the results of our efficacy study.^{4,5} Other organizations, such as the Aphasia Institute in Toronto, utilize highly trained volunteers. The decision to use volunteers versus professionals can be a complex one.^{1,9-15} Again, there is no one “right” answer to this issue, but it requires thoughtful consideration.

If you are starting the organization, but you will also need to be working elsewhere for a paycheck, you must decide how much time you can realistically spend on a new project. Similar to the space decisions discussed above, the need for your time as well as staffing decisions will be determined by the goals and the resources of the organization. These decisions are not static—they are likely to evolve over the life of the organization.

If You Build It, Will They Come?

Once you have determined the goals, location, and staffing for your aphasia center, how will you get the word out about your new program? It is important to determine the steps you will take to reach potential clients regarding the new program. Some marketing methods are low cost. These include e-mail or inexpensive flyers that are sent to colleagues and community referral sources. Depending on the community and your access to various media outlets, you may be able to interest a journalist in writing a story about the proposed center. Other marketing methods involve a greater investment in time and money. These include printed marketing materials and developing an independent Web site. These tools need to be part of an organization’s budget and may be critical for reaching potential clients and funders.

Although the ACC has been fortunate to have had assistance creating its Web site more

than 10 years ago, we have just started using a designer to develop other marketing materials. Until this time, we found that one-page flyers, created with word-processing software, met our immediate needs and was a better use of our limited resources.

Size of Your Community?

One factor that may greatly impact your organization, but that you won't have control over, is the size of the community in which you are located. Given the lack of awareness of aphasia,^{16,17} organizations located in smaller communities may have advantages in raising awareness of aphasia, resulting in more marketing and fund-raising opportunities. Larger communities result in a greater number of organizations, all competing for a limited pool of resources. This may make it more challenging for a new or small organization to gain the attention of media outlets or potential funders in large communities. Given the disorder of aphasia, with poor name recognition, there may be definite advantages to operating in a small community and being a bigger fish in a smaller pond.

CONCLUSION

In the future, when I am asked by speech-language pathologists whether they should start an aphasia center, my answer will be "maybe." If they can articulate goals for the organization that meet the unmet needs of people with aphasia in their own communities, and if they are willing to commit themselves to working long hours with fewer resources, they are ready to move forward on an arduous but potentially rewarding journey.

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