

Management of aphasia has traditionally focused largely on language impairments, but recently, programs began to target aphasia's consequences such as social isolation, reduced sense of well-being, or diminished participation in favored activities. One means of addressing these consequences is via an "aphasia center." Such centers provide programming designed expressly for people with aphasia and, often for family members as well. These aphasia programs differ from more traditional approaches and typically offer services such as conversation groups or participation oriented activities. There has been much recent interest by professionals and people with aphasia and their families in finding out more about "aphasia centers", including types of programming and funding sources. We could find no directory or description of programs, organizations or facilities specifically described as aphasia centers. In fact, we found no definition of what constitutes an aphasia center. Therefore, we undertook an online survey to identify and describe aphasia centers in North America.

Method

The survey was designed, piloted and refined, with 34 questions resulting. Questions elicited numeric and demographic data, multiple choice responses regarding programming issues, and open ended questions concerning goals and mission statements. The survey was posted on the Internet using SurveyMonkey.com. An introductory letter was distributed via electronic mail to members of the American Speech-Language-Hearing Association Special Interest Division 2 listserv and to a distribution list gleaned from a registry of rehabilitation programs compiled by the National Aphasia Association. The letter described the survey purpose and directed potential participants to the website. Data were collected over 3 months; then responses involving frequency counts were analyzed using SurveyMonkey software; the other responses were downloaded for qualitative analysis.

Results

Thirty-one responses were received; not all respondents answered all questions. The results will be explicated via text, tables and figures in the actual presentation. Dominant trends in the data are explained below.

Demographics: Although 1/3 of the programs were located in the Northeastern US, programs were in existence across the nation's geographical regions and in Canada. Twenty-five programs reported dates of inception ranging from 1979 to 2009. Interestingly, 19 of them opened their doors since 2000, validating our impression of growing interest in this form of client support. The number of clients served per year ranged from 9 to 269 (Mean=63) indicating wide variations in size.

Mission: Twenty-eight programs reported having a mission statement, with a variety of missions; rebuilding lives and increasing life engagement (9), improving communication (9) and assisting families (10) were the most prevalent.

Admission and Discharge: Twenty-one respondents reported specific admission criteria, both inclusionary and exclusionary. Again, multiple criteria were the norm, with (not surprisingly) diagnosis of aphasia and ability to participate predominating. Personal characteristics such as endurance, independence in self-care and interest in participating were also prevalent. Exclusionary criteria included presence of dementia and disruptive behavioral. Only 10 programs had discharge criteria; rather most programs consider "discharge" to be at the discretion of clients and caregivers.

Program Logistics: Almost half of the programs (43%) provide an average of 4-6 hours of client participation. One-third of the programs were more abbreviated, with 3 hours or fewer of participation. The remainder exceeded 6 hours. Interestingly, most of the programs exceeded the typical 1 or 2 hours of weekly intervention. Program schedules varied widely; most were built around semesters or terms or operated continuously with ongoing addition of new members. Programs also varied as a result of affiliation. Twelve programs were independent. Nine were University or college related; 6 were affiliated with healthcare programs. The remainder reported “other” affiliations. The clear majority of programs reported renting space or having space provided by other organizations.

Staffing: The majority of centers have both CEOs and program directors, and half have boards of directors, involving community leaders, healthcare professionals, persons with aphasia or family members, and/or financial contributors. Board members are involved typically in fiscal management and fund raising, and to a lesser degree in programming and advocacy. One third of programs have marketing directors or fund raisers.

Staffing is remarkably varied; 27 employ one or more SLPS, but social workers, psychologists, recreation and exercise coordinators, music, physical, occupational therapists are involved in almost half of the programs. Most programs also involve part time staff; in addition, almost half utilize volunteers.

Funding. Only 6 centers were reported as “for-profit”. For most, funding comes largely from fee for services, donations, fund raising and grants. Roughly half of the centers charge by the term, with sliding fees or scholarships available in the majority. Other forms of funding include hourly, weekly or monthly rates.

Programming options. Overwhelmingly, the most widely offered service was conversation groups. At least half of the centers offered the following: computer activities, outings, individual therapy, writing and reading groups, games, life skills activities or educational programs. Many additional services were offered, including counseling, advocacy, exercise, art, theater and drama. Twenty nine programs reported providing support groups and/or educational programs and counseling for caregivers. Programs offered to the community included aphasia awareness programs and supported conversation training at 19 centers. Twenty-seven of the 31 programs provided opportunities for clinical practicum experiences.

Assessment. Thirty programs measured outcomes of program service using measures such as satisfaction ratings, goal achievement, scales, psychosocial measures, and nonstandard measures such as evidence of increased communicative interaction. Standard tests were used in 9 programs.

Marketing/Public relations. Twenty-eight programs publish brochures describing services. Twenty publish a newsletter, 23 have websites, and 13 offer products for purchase.

Discussion

Most respondents were extremely enthusiastic about the aphasia center concept and felt that it offered something that traditional aphasia therapy does not. Respondents were divided in their belief that aphasia centers are an adjunct to traditional language therapy versus a better option for people with aphasia. The following concepts that define an “aphasia center” were gleaned from respondent text responses. *Group interaction* was cited as a key to the aphasia center concept; respondents felt that groups allow

participants to experience success, practice communicating and participate in a natural communication environment. Because of the multiple offerings of many aphasia centers, therapy can be more *intensive*. Several respondents noted that the potential for *improvement in psychosocial well-being* is a particular advantage of aphasia centers; this was related to feeling accepted, getting support, learning from peers, having choices, feeling empowered and making friends. In addition, the idea of a *community* in which members share common goals and participate with others appeared important to the aphasia center concept.

A number of respondents felt that aphasia centers differed from traditional language therapy in the following ways: the *focus is on living with aphasia* over the *long term*; the idea of social *engagement and participation* is key; program offerings and support extend to *all those affected by aphasia* and *aphasia advocacy and awareness* are often important goals. Clearly not all of these characteristics are represented in all of the centers responding to the survey; however, these are relevant themes that arose in text descriptions and help to provide insight into the concept of an aphasia center.