Aphasia Centers: A Growing Trend in North America

This issue of *Seminars in Speech and Language* addresses a relatively new service delivery option in aphasia treatment—the “aphasia center.” Although the first aphasia center was founded over 30 years ago, it is only within the past 10 years that considerable interest has been devoted to this form of aphasia intervention. This interest is related, at least in part, to the shifting focus from treatment entirely devoted to remediating the language impairment associated with aphasia, to intervention aimed at multiple consequences of aphasia such as difficulty carrying out life roles, diminished participation in favored activities, and reduced self-esteem. This expansion of aphasia treatment has been variously labeled the “life participation approach,” “social model intervention,” and the “functional-social approach.” The growing interest in intervention that addresses life participation and social barriers in aphasia is likely due to several factors including challenges raised by the worldwide disability movement, grass roots efforts by clinicians to address more relevant and meaningful goals, and changes in funding patterns in health care. In addition, the advent of the World Health Organization International Classification of Functioning, Disability and Health (WHO ICF) provides a framework for targeting intervention beyond the aphasic language impairment. Clinicians began to realize that remediating the long-term consequences of aphasia was ill suited to traditional health care services—services that are both highly structured and often of relatively short duration. Aphasia center programs began to appear in which people with aphasia could participate in relatively intensive, varied, and long-term programming.

Because aphasia center programming is a relatively recent phenomenon, little has been published regarding the philosophy, organization, and offerings associated with aphasia centers, and research evidence documenting the effectiveness of aphasia centers is difficult to acquire. Although elements of aphasia center programming have demonstrated treatment efficacy (e.g., group aphasia therapy), research evidence supporting the unique “program package” offered by aphasia centers is scarce (with one exception offered by van der Gaag and colleagues based on research in Great Britain). Therefore, this issue serves as an “authority-based” introduction to the aphasia center concept, with several contributions by experienced clinicians who have founded or currently manage aphasia centers in North America.

The opening article by Simmons-Mackie and Holland sets the stage for subsequent articles by defining what we mean by an “aphasia center” and identifying key features of existing aphasia centers based on results of an online survey. Their findings reinforce the belief that this is a growing trend, with the number of centers increasing dramatically in the past 10 years.

Kagan describes a conceptual framework, Living with Aphasia: Framework for Outcome Measurement (A-FROM), and discusses applications of the framework at the Aphasia Institute in Toronto. She explains the use of A-FROM, a user-friendly and aphasia-specific adaptation and expansion of the WHO ICF, to clarify the mission of the aphasia center, describe the range and rationale for direct services, and help identify gaps in programming. A-FROM includes four key domains.
(language processing, life participation, personal/psychosocial factors, and communication environment) that interact and overlap to create “life with aphasia,” a concept similar to quality of life. Interestingly, Kagan’s introduction of A-FROM and the WHO ICF provide this issue with a context for situating several other articles.

For example, Cherney, Oehring, Whipple, and Rubenstein describe a unique program offered for people with aphasia at the Rehabilitation Institute of Chicago’s Center for Aphasia Research and Treatment. In effect, this program focuses explicitly on participation in a communicative event or activity as defined in the WHO ICF/A-FROM framework. Combining the skills of speech-language pathologists and drama therapists, people with aphasia were guided through the process of developing, scripting, and performing a play. This drama class is an excellent example of a socially situated method of addressing communication, confidence, and life participation in aphasia.

Welsh and Szabo describe a program for training potential communication partners of people with aphasia, specifically nursing assistant students. This training demonstrates an explicit focus on improving the communicative environment of people with aphasia as defined by the ICF/A-FROM framework. Based on the premise that communication and participation in communicative events can be enhanced when other people are knowledgeable and skillful, staff and clients with aphasia at the Adler Aphasia Center in Maywood, New Jersey are attempting to improve communicative access to health care by training health care staff. Also, the program employs the expertise and experiences of people with aphasia who serve as educators in the training program, thus providing an opportunity for authentic and meaningful participation. Like the drama program described by Cherney and colleagues, the Adler Aphasia Center training goes beyond simply educating the public. Rather, it demonstrates the key involvement of people with aphasia in planning and implementing a program offering. This focus on consumer involvement and choice demonstrates a key element of social model values.

Silverman describes key issues that she faced in founding the Triangle Aphasia Project and offers solutions based on her own experiences as an expert. Particularly interesting is her description of the Individualized (Re)engagement Plan as a method of identifying and addressing real-life participation goals of clients with aphasia. Although the explicit outcome goals of these plans are participation oriented, Silverman describes ways to focus treatment not only on participation but also on the ICF domains of psychosocial/personal factors (e.g., confidence) and environment (e.g., setting, communication partners).

This special issue closes with Elman’s tutorial on starting an aphasia center. Buoyed by the enthusiasm of clients and the increasing number of aphasia centers and frustrated with limited funding and narrowly focused treatment options in traditional health care settings, many clinicians have expressed interest in starting an aphasia center. Elman draws on her experiences founding the Aphasia Center of California along with key references to business resources to provide a valuable resource to clinicians.

This issue of Seminars in Speech and Language offers an authority-based description of an innovative and growing trend in aphasia intervention. We hope that the description of various aspects of aphasia center development, organization, and programming will stimulate interest in and research on the aphasia center concept.

Nina Simmons-Mackie, Ph.D., BC-ANCDS
Guest Editor

REFERENCES


