

Life Participation Approach to Aphasia: A Statement of Values for the Future

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Unprecedented changes are occurring in the way treatment for aphasia is viewed – and reimbursed. These changes, resulting from both internal and external pressures, are influencing how speech-language pathologists carry out their jobs.

Internal influences include a growing interest in treatments that produce meaningful real life outcomes leading to enhanced quality of life. Externally, we are influenced by disability rights activists encouraging adjustments in philosophy and treatment and by consumers frustrated by unmet needs and unfulfilled goals. Most recently, a strong external influence is emanating from the curtailment of funding for our work that has caused a significant reduction in available services to people affected by aphasia.

To accommodate these varied influences on service delivery, it is important to take a proactive stance. We therefore propose a philosophy of service delivery that meets the needs of people affected by aphasia and confronts the pressures from our profession, providers, and funding sources.

Our statement of values has been guided by the ideas and work of speech-language pathologists as well as by individuals in psychology, sociology, and medicine. We intend neither to prescribe exact methods for achieving specific outcomes, nor to provide a quick fix to the challenges facing our profession. Rather, we offer a statement of values and ideas relevant to assessment, intervention, policy making, advocacy, and research that we hope will stimulate discussion related to restructuring of services and lead to innovative clinical methods for supporting those affected by aphasia.

DEFINING THE APPROACH

The “Life Participation Approach to Aphasia” (LPAA) is a consumer-driven service-delivery approach that supports individuals with aphasia and others affected by it in achieving their immediate and longer term life goals (note that “approach” refers here to a general philosophy and model of service delivery, rather than to a specific clinical approach). LPAA calls for a broadening and refocusing of clinical practice and research on the consequences of aphasia. It focuses on re-engagement in life, beginning with initial assessment and intervention, and continuing, after hospital discharge, until the consumer no longer elects to have communication support.

LPAA places the life concerns of those affected by aphasia at the center of all decision making. It empowers the consumer to select and participate in the recovery process and to collaborate on the design of interventions that aim for a more rapid return to active life. These interventions thus have the potential to reduce the consequences of disease and injury that contribute to long-term health costs.

THE ESSENCE OF LPAA

We encourage clinicians and researchers to focus on the real-life goals of people affected by aphasia. For example, in the initial stages following a CVA, a goal may be to establish effective communication with the surrounding nursing staff and physicians. At a later stage, a life goal may be to return to employment or participation in the local community.

Regardless of the stage of management, LPAA emphasizes the attainment of re-engagement in life by strengthening daily participation in activities of choice. Residual skill is thus seen as only one of many requisites. For example, full participation is dependent on motivation and a consistent and dependable support system. A highly supportive environment can lessen the consequences of aphasia on one’s life, whatever the language impairment. A nonsupportive environment, on the other hand, can substantially increase the chance of aphasia affecting daily routines. Someone with mild aphasia in a nonsupportive environment might experience greater daily encumbrances than another with severe aphasia who is highly supported.

In this broadening and refocusing of services, LPAA recommends that clinicians and researchers consider the dual function of communication – transmitting and receiving messages and establishing and maintaining social links. Furthermore, life activities do not need to be in the realm of communication in order to deserve or receive intervention. What is important is to judge whether aphasia affects the execution of activities of choice and one's involvement in them (see Table 1 for a few examples of how LPAA may lead to a broadening and refocusing of services).

THE ORIGINS OF LPAA

Functional and Pragmatic Approaches

LPAA draws on ideas underlying functional and pragmatic approaches to aphasia and shares some common values with those who take a broad approach to functional communication treatment by focusing on life participation goals and social relationships. In our view, however, the term “functional” does not do justice to the breadth of this work. In addition, the term is often used narrowly to mean “functional independence in getting a message across.” Although LPAA recognizes the value of this type of impairment-level work, it should form part of a bigger picture where ultimate goal for intervention is re-engagement into everyday society.

Human Rights Issues and Consumers' Goals

LPAA is a means of addressing unmet needs and rights of individuals with aphasia and those in their environment. Indeed, the Americans with Disabilities Act (ADA), signed into law on July 26, 1990, requires that physical and communication access be provided for individuals with aphasia and other disabilities and allows them legal recourse if they are blocked from accessing employment, programs, and services in the public and private sectors.

In 1992, ASHA provided guidelines for a “communication bill of rights” (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities). Its preface states that “all persons, regardless of the extent or severity of their disabilities, have a basic right to affect, through communication, the conditions of their own existence.” Communication is defined as “a basic need and basic right of all human beings” (p. 2). ASHA thus views communication as an integral part of life participation.

Emphasis on Competence and Inclusion

LPAA philosophy embraces a view of treatment that emphasizes competence and inclusion in daily life, focusing as much on the consequences of chronic disorders as on the language difficulty caused by the aphasia. Along with other movements in education and health care, LPAA shifts from a focus on deficits and remediation to one of inclusion and life participation (see Fougeyrollas et al., 1997; WHO, ICIDH-2, 1997). Such international changes in focus point to the need to address the personal experience of disability and promote optimal life inclusion and reintegration into society.

Changes in Reimbursement and Service Delivery

Health care and reimbursement in America have undergone an unprecedented overhaul. Financial exigencies have led to an emphasis on medically essential treatments and others seen as likely to save on future health care costs. Many of the incentives in this model result in the provision of efficient short-term minimal care, rather than the longer term, fuller care supported in the past.

LPAA represents a fundamental shift in how we view service delivery for people confronting aphasia. Since LPAA focuses on broader life-related processes and outcomes from the onset of treatment, service delivery and its reimbursement will require novel means that stand outside most current practices. We are confident that cost-sensitive and therapeutically effective models are possible. Our purpose in this introductory article is to prompt a discussion with providers and consumers as to whether life participation principles and values should play a more central role in the delivery and reimbursement of future service delivery for all those affected by aphasia.

THE CORE VALUES OF LPAA

LPAA is structured around five core values that serve as guides to assessment, intervention, and research.

The Explicit Goal Is Enhancement of Life Participation

In the LPAA approach, the first focus of the client, clinician, and policy-maker is to assess the extent to which persons affected by aphasia are able to achieve life participation goals, and the extent to which the aphasia hinders the attainment of these desired outcomes. The second focus is to improve short- and long-term participation in life.

All Those Affected by Aphasia Are Entitled to Service

LPAA supports all those affected directly by aphasia, including immediate family and close associates of the adult with aphasia. The LPAA approach holds that it is essential to build protected communities within society where persons with aphasia are able not only to participate but are valued as participants. Therefore, intervention may involve changing broader social systems to make them more accessible to those affected by aphasia.

The Measures of Success Include Documented Life-Enhancement Changes

The LPAA approach calls for the use of outcome measures that assess quality of life and the degree to which those affected by aphasia meet their life participation goals.

Without a cause to communicate, we believe, there is no practical need for communication. Therefore, treatment focuses on a reason to communicate as much as on communication repair. In so doing, treatment attends to each consumer's feelings, relationships, and activities in life.

Both Personal and Environmental Factors Are Targets of Intervention

Disruption of daily life for individuals affected by aphasia (including those who do not have aphasia themselves) is evident on two levels: personal (internal) and environmental (external). Intervention consists of constantly assessing, weighing, and prioritizing which personal and environmental factors should be targets of intervention and how best to provide freer, easier, and more autonomous access to activities and social connections of choice. This does not mean that treatment comprises only life resumption processes, but rather that enhanced participation in life "governs" management from its inception. In this fundamental way, the LPAA approach differs from one in which life enhancement is targeted only after language repair has been addressed.

Emphasis Is on the Availability of Services as Needed at All Stages of Aphasia

LPAA begins with the onset of aphasia and continues until consumers and providers agree that targeted life enhancement changes have occurred. However, LPAA acknowledges that life consequences of aphasia change over time and should be addressed regardless of the length of time post-onset. Consumers are therefore permitted to discontinue intervention, and reenter treatment when they believe they need to continue work on a goal or to attain a new life goal.

CONCLUSIONS

Our health-care systems are undergoing change and, as a result, so are our professions. How we allow this change to affect our clinical practice, our research directions, and our response to consumer advocacy is up to us. We need to educate policy-makers that being fiscally responsible means having a consumer-driven model of intervention focusing on interventions that make real-life differences and minimize the consequences of disease and injury.

While it is clear that the implicit motivation underlying all clinical and research efforts in aphasia is related to increased participation in life, the path to achieving that goal is often indirect. Because LPAA makes life goals primary and explicit, it holds promise as an approach in which such goals are attainable. We invite other speech-language pathologists to join us in discussing and developing life participation approaches to aphasia.

Table 1 Examples of the Shift in Focus of Life Participation Approach to Aphasia

LCAA	Examples of Shift in Focus
Assessment includes determining relevant life participation needs and discovering clients' competencies	In addition to assessing language and communication deficits, clinicians are equally interested in assessing how the person with aphasia does <i>with support</i>
Treatment includes facilitating the achievement of life goals	In addition to work on improving and/or compensating for the language impairment, clinicians are prepared to work on anything in which aphasia is a barrier to life participation (even if the activity is not directly related to communication)
Intervention routinely targets environmental factors outside of the individual	In addition to working with the individual on language or compensatory functional-communication techniques, clinicians might train communication partners or work on other ways of reducing barriers to make the environment more "aphasia-friendly"
All those affected by aphasia are regarded as legitimate targets for intervention	In addition to working with the individual who has aphasia, clinicians would also work on life participation goals for family and others who are affected by the aphasia, including friends, service providers, work colleagues, etc.
Clinician roles are expanded beyond those of teacher or therapist	<p>In addition to doing therapy, clinicians might take on the role of:</p> <ul style="list-style-type: none"> • "communication partner," and give the person with aphasia the opportunity to engage in conversation about life goals, concerns about the future, barriers to life participation, etc. • "coach," "problem solver," or "support person" in relation to overcoming challenges in reengaging in a particular life activity
Outcome evaluation involves routinely documenting quality of life and life participation changes	<p>In addition to documenting changes in language and communication, clinicians would routinely evaluate the following in partnership with clients:</p> <ul style="list-style-type: none"> • life activities and how satisfying they are • social connections and how satisfying they are • emotional well-being

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