

Neurogenic Communication Disorders and the Life Participation Approach

THE SOCIAL IMPERATIVE IN SUPPORTING INDIVIDUALS AND FAMILIES

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PREFACE

*W*hen Amy Hanson from SpeechPathology.com asked me to organize a symposium on Life Participation in Aphasia for their online educational service, I jumped at the chance. The symposium was to be conducted for one week, one hour a day for five weekdays. And I knew immediately what I wanted to do: capture one writer of the LPAA statement, and surround her with four “youngsters” to the 20+ year-old movement. Roberta Elman was my first choice, and she said yes. I then gathered a list of possible others, which was considerable, and rather arbitrarily chose four who had different interests, to join Roberta. I wanted relative newbies, because I thought it was time for new voices to be heard, but I had scads of backups. (The world is changing!!) AND all four said yes! I, who am a visual rather than auditory learner, planned to listen to all the webinars, of course, but with pain. Surprise! When Friday rolled around and it was over, I had learned, and enjoyed every single minute of the listening. Thinking to strike while the iron was still hot, I called each participant and asked (Roberta first) if they would be interested in turning the whole thing into a book. Once again, all said yes! And I decided to reach into my bag of tricks and find a few more. Once again, original speakers were joined by two more first choices, and we were off and running. You will note that some of the co-authors might have more familiar names. First authors chose them, as they saw fit. Others went with less familiar people. Finally, we felt flattered when Nina Simmons-Mackie agreed to take a last look over everyone’s efforts. So what we have here are essentially young voices, joined in some cases by other young voices, or by more experienced ones. We hope you enjoy, but more importantly LEARN from reading our efforts about the history of the movement, some treatment and assessment approaches that can fit into the strictures of current day health care, and provide ideas for moving away from simply concentrating on the impairments but moving on to how whose impairments have impact on everyday life.

—ALH

When Audrey Holland asked me to be part of the webinar series, I was truly honored and excited! Being part of a project that focused on helping clinicians apply a life participation approach to their own practice had become part of my life's mission. And my excitement rose higher when Audrey shared the idea of creating a book based on the five webinars, plus adding contributions from a few others. The current book represents our collective efforts.

In the prologue to the book, you will find the Life Participation Approach to Aphasia (LPAA) article that was originally published in the *ASHA Leader* in 2000. This serves as a foundation for the nine chapters that follow. First up is Audrey's chapter. In it, she weaves her personal career together with the "life participation movement" and its leaders throughout the English-speaking world. In Chapter 2, I share the ups and downs of my own career trajectory toward implementing LPAA, ending with development of the C.A.P.E. checklist. Sarah Baar, in Chapter 3, shares her tips, tricks, and tools for bringing LPAA into your own clinical practice. In Chapter 4, Tom Sather and Tami Howe focus on the important role of the environment in supporting language, communication, and participation, especially for individuals who are living with aphasia. Katie Strong and Barbara Shadden, in Chapter 5, reveal the benefits of helping clients to share their own personal narratives, in order to support identity. In Chapter 6, Becky Khayum and Aimee Mooney provide clinicians with a roadmap for incorporating person-centered intervention, especially for clients who are living with primary progressive aphasia. Natalie Douglas and Delainey Smyth, in Chapter 7, show clinicians how they can apply a life participation intervention approach for people living with dementia. In Chapter 8, Peter Meulenbroek and Louise Keegan, share how to apply a life participation focus for those with traumatic brain injury. And, finally, in Chapter 9, Nina Simmons-Mackie completes the book with her thoughts on the past, present, and future of LPAA.

—RJE

We hope you find this book inspiring and relevant to your present or future clinical practice!

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Audrey: In remembrance of four visionaries: Mike Adler, Pat Arato, Shirley Morgenstein, and Claire Penn.

Roberta: To the people and creatures who have enriched my life participation . . .

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PROLOGUE

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

LPAA Project Group

(in alphabetical order): *Roberta Chapey, Judith F. Duchan, Roberta J. Elman, Linda J. Garcia, Aura Kagan, Jon G. Lyon, and Nina Simmons-Mackie*

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

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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 0–1 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 the ultimate goal for intervention is re-engagement into everyday society.

Table 0–1. Examples of the Shift in Focus of Life Participation Approach to Aphasia

LPAA	Examples of Shift in Focus
<p>Assessment includes determining relevant life participation needs and discovering clients' competencies.</p>	<p>In addition to assessing language and communication deficits, clinicians are equally interested in assessing how the person with aphasia does with support.</p>
<p>Treatment includes facilitating the achievement of life goals.</p>	<p>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).</p>
<p>Intervention routinely targets environmental factors outside of the individual.</p>	<p>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.”</p>
<p>All those affected by aphasia are regarded as legitimate targets for intervention.</p>	<p>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.</p>
<p>Clinician roles are expanded beyond those of teacher or therapist.</p>	<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
<p>Outcome evaluation involves routinely documenting quality of life and life participation changes.</p>	<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.

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.

Everyone Affected by Aphasia Is 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.

Success Measures 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 Intervention Targets

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.

Short List of References Published with the Original Article

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For the detailed list of references published with the original article, please go to the Aphasia Institute's website: <http://www.aphasia.ca>



THE SOCIAL IMPERATIVE FOR APHASIA REHABILITATION

A PERSONAL HISTORY

Audrey L. Holland

*A*phasia is not life threatening, but it stops people from having a life.

—Pat Arato, “The Language Thief”

Background

Roberta and I deliberately chose younger clinicians and researchers to write chapters in this book, although they were free to choose the “older guard” as coauthors. We believe that fresh new approaches are badly needed so that the “Social Imperative” can continue to grow and be productive. My task was to share its 50-year-old history as I have seen it develop to this point.

Isn't the Social Imperative what good therapy is all about? Well, yes and no. I believe that test score changes and more focused pre-post changes as a result of specific, language-focused training regimens, are of equal value. Understanding the impairments and learning to use the specific techniques that improve core language impairments are vitally important. We know that for aphasia and TBI, improvement is likely to occur as a function of appropriate, impairment-focused treatment. However, it is not enough. For individuals with dementia and PPA, the scenario is different. Here, the goal is to help people maintain their language skills for as long as possible.

There is another problem as well. The current health care system fails to recognize that all of these disorders are chronic. Only limited benefits extend beyond the earliest periods of actually living with the disorder. This, then, is part of the Social Imperative. Under the current circumstances, how can the lingering consequences be minimized most efficiently and effectively? It is extremely important for prospective clinicians that their curricula be rearranged so that they can learn about these concerns and newer, impairment-focused intervention skills that address them.

A Brief, Clinically-Focused History of Aphasia Study

The elusive and exotic language disorder called aphasia that frequently accompanies brain injury or other neurologic conditions has intrigued physicians, philosophers, and scientists since 3500 BC (Benton & Joint, 1960). Their interest was (and still seems to be) how aphasia could inform questions of the neuroanatomical localization of language, as well as furthering our understanding of human beings' unique ability to have developed and use it.

Concern with what could be done to rehabilitate language, although sporadic before the end of World War I, became intense in Germany and Russia as the war ended, and as young, head-injured men struggled to live normal lives despite their difficul-

ties in speaking and talking. The United States and most of the English-speaking world, however, showed only limited interest before the conclusion of World War II.¹ The increased interest was due to the influx of substantial numbers of head-injured veterans coming home after that war. In the United States, hospitals and training programs were developed at military and then Veteran's Administration hospitals across the country. The pioneers in this effort included Hildred Schuell, Ollie Backus, Jon Eisenson, and Kurt Goldstein (bringing his European knowledge) among many others.

Foremost among these was Joseph Wepman, who directed the program at DeWitt General Hospital in California. Dr. Wepman's *Recovery from Aphasia* (1951) became my Sirius, my guide star. But it was all fairly abstract for me, because I did not even know anybody with aphasia until after I obtained my doctorate. I was just intrigued by the problem.

My personal history in aphasia started in the early 1960s, when I took my first academic job at Emerson College in Boston, also the location of the renowned Boston VA Hospital. I managed to talk my way into attending the Aphasia Grand Rounds there, conducted by Norman Geschwind, Harold Goodglass, Edith Kaplan, and Robert Sparks, who all took pity on me and became my mentors. I finally met my first person with aphasia there.

At that time, I was a flaming behaviorist, planning to remedy aphasia with carefully chosen language stimuli based on frequencies of occurrence and such abstract notions, flawlessly appropriate schedules of reinforcement, and well-developed techniques for shaping behavior and such. The VA was a spectacular place to see creative personal, impairment-focused work in assessment and treatment as it was conducted by Sparks, Goodglass, Kaplan, and a bit later, by Nancy Helm-Estabrooks. Nevertheless, I persisted (so to speak). I held fast to my behaviorist principles and planned to adapt all of the wonderful things I was learning into Skinnerian terms.

But being in the rich intellectual world of Boston and Cambridge, I found myself intrigued with other thoughts, of my own

¹A very concise history of aphasia can be found on the internet by searching for "History of Aphasia."

thoughts, such as: If aphasia is a language disorder, a language is used to communicate, to fully relive life, and to get along with others, then aphasia must surely affect the larger world of communication, not just its language part!

This was the heyday for people who were interested in what was coming to be known as language pragmatics. This was nuanced, perhaps, but clearly a more real world of speakers and listeners collaborating to exchange messages. This was the world of Grice (1975) with his timeless Cooperative Principles for how speakers and listeners interact to create verbal interaction; of Austin, (whose influence was well known then but his earlier Harvard essays were not published until 1975); and Searle's (1969) incisive analysis, "Speech Acts," that is, that meaning results from interaction between speakers and listener. I thought it was extremely important to try to connect language pragmatics to aphasia rehabilitation. I pondered what is still one of my favorite rationales, that of Watzlawick, Beavin, and Jackson (1967) to the effect that "Humans cannot not communicate." So, I read a lot, and strived to attend a lot of the endless number of lectures that contributed so much to the Boston-Cambridge intellectual reputation.

AND I finally began to work with my first aphasic client. MS was a young graduate student when he incurred aphasia as a result of an arteriovenous malformation (AVM) bleed. He was bright, eager, and optimistic about working hard to bring about his (substantial) recovery. We slogged through a whole lot of behavioral training, and MS certainly improved. But somehow, my role seemed more related to my counseling background than to my stimulus-response skills. I was far more interested in how his changed career plans, his negotiations through life, and his marriage were influenced by his aphasia. I just didn't know what to do about any of it, except to listen and to counsel, and make tentative suggestions for him to try out. I don't quite know how I helped, but, he survived me. MS went on to become a successful marriage counselor with a solid clinical reputation. And at least my "treatment" caused no long-term harm.

And that is how I began to discover who I think I am today. I probably would have gotten here sooner or later, but it would have taken much longer if I had not encountered the Boston Veterans Administration Hospital, language pragmatics, communication, and finally, the work of Martha Taylor Sarno.

Martha Taylor Sarno and the Functional Communication Profile (FCP) (1969)

Sarno's inventory, the FCP, was published at the end of that decade. This was a big step away from available tests of language impairment and loss. It made perfect sense to me: asking systematic questions about how someone was getting along after aphasia has entered their everyday lives and finding out about the areas that were working well despite aphasia . . . or not. THIS is what was aphasia rehabilitation should be about.

Martha Taylor Sarno is the Founding Mother of the Social Imperative. She initiated the Social Imperative by exploring how persons with aphasia (PWA) and their spouses go about getting on with life, not necessarily what the "experts" might have to tell them about language processing and word retrieval. Sarno had to have recognized the Social Imperative before 1969, of course. However, it seems safe to assume that her priceless contribution to "functional communication" in the fullest sense of the word, began in 1969, and essentially has never stopped. It is important to note that Martha Sarno went on to form the National Aphasia Association (NAA). Its reins were handed over to the multi-talented Darlene Williamson in 2012, and since then, the NAA has continued to grow, thrive, and make significant contributions to living well with aphasia. It is also true that Sarno was a founding member of the impairment-research oriented Academy of Aphasia, a group she (nor I) never abandoned. I feel comfortable in her and my shared beliefs that both the impairment of aphasia and its consequences require our research and clinical attention.

This is being written in 2019, which is the Golden Anniversary of the Social Imperative in American Aphasiology. The FCP has since been joined by what seem to me to be hundreds of inventories looking at hundreds of aspects of social communication in aphasia and other language disorders, tons of ways to measure and to treat it. Nevertheless, it started with the FCP inventory.

The 1960s also figured prominently in the early history of the Social Imperative in a therapeutic way. In 1965, the American actress, Patricia Neal, suffered a life-threatening and aphasia-producing cerebral aneurysm. Her return to health and the