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IMPLEMENTATION OF THE LIFE PARTICIPATION APPROACH TO APHASIA IN AN APHASIA CENTER INTEGRATED WITHIN AN ACADEMIC COMMUNICATION DISORDERS DEPARTMENT

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Introduction

The Life Participation Approach to Aphasia (LPAA) offers a paradigmatic shift in the way practitioners view aphasia intervention, focusing on meeting the needs of individuals and their families affected by aphasia. It has been shown that LPAA can generate natural, meaningful enhancement to the quality of life of persons with aphasia (PWA) by transitioning from a medical to a social model of health care and disability (Holland & Elman, 2021). This evolutionary model follows the inclusion of a new framework, the International Classification of Functioning Disability and Health (ICF), published by the World Health Organization (WHO, 2001), along with the publication of the LPAA (LPAA Project Group, 2000).

This paradigmatic shift in aphasia intervention has been implemented since 2007 at the Adler Aphasia Center of the Department of Communication Disorders, Hadassah Academic College (HAC), Jerusalem. Most aphasia centers are based on a service delivery model that provides an interactive community for PWA and their families during the chronic stage (Elman, 2016). The Adler Aphasia Center is physically located and integrated within the Communication Disorders Department, thereby offering significant advantages in establishing the LPAA framework. The LPAA is implemented by educating and creating an active community for PWA. The geographical location of the Adler Aphasia Center dictates the multilingual and multicultural character of its participants, with multicultural

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issues influencing all aspects of decision-making. The clinical education program for students at HAC is based upon three main axes: evidence-based learning; reflective practice; and case-based learning (Meilijson & Katzenberger, 2009). The center serves as one of the clinical placements where students perform their clinical practice with PWA and their families. The implementation of the LPAA will be discussed through a presentation of specific vignettes from the activities taking place at the center.

The Implementation of LPAA within Aphasia Centers

According to the traditional medical model, illness and disability are perceived as located within the patient. Consequently, a healthcare provider offers treatment with the desired outcome being a cure for the illness – although persons with aphasia typically do not recover fully, but remain living with communication deficits (Elman, 2016). A social model of healthcare, however, views illness and disability as an interaction among personal, physical, environmental, and societal factors, with the desired outcome being to promote positive functional change even when a cure is not possible. The ICF classification, which integrates medical and social models, requires healthcare professionals to look beyond the impairment and illness and consider domains of body structure and function, activities, and participation, as well as contextual factors (environmental and personal) (Reed et al., 2005).

A transformative document in the area of aphasia intervention entitled "Life Participation Approach to Aphasia - A Statement of Values for the Future" was presented in 2000 by a group of expert aphasiologists (the LPAA Project Group, 2000) (see also chapter 12, this volume). One of the positive developments that followed this statement of values was the formation of aphasia groups in several parts of the world (Canada, USA, New Zealand, and UK), that focused on life participation (Holland & Elman, 2021). Furthermore, Elman and Bernstein-Ellis (1999a) provided evidence for the efficacy of group communication treatment. Participants who took part in group communication treatment demonstrated significant improvements in linguistic and communicative outcomes as well as psychosocial adjustment changes. The LPAA statement and growing evidence of positive outcomes of working in groups led to a proliferation of aphasia centers worldwide (Elman, 2016; Holland & Elman, 2021; Woelders et al. 2018).

Aphasia centers are based on a service delivery model that provides an interactive community for PWA and their families during the chronic stage. Centers offer diverse programs providing tools and support for PWA and their families and a variety of activities based on the life participation approach (Woelders et al., 2018). Activities may include communication groups, partner training programs, support for family members, individual therapy focusing on participation goals, implementation of augmentative and alternative communication (AAC) tools, and more. All these activities share a common underlying belief system regarding the potential for learning to live successfully with aphasia by offering interventions aimed at "Living with Aphasia" (Kagan, 2011).

In order to plan and capture meaningful life participation outcomes, many aphasia centers adopted the Living with Aphasia Framework for Outcome Measurement (A-FROM) (Kagan et al., 2008). The A-FROM captures intervention and outcome domains that are relevant for aphasia centers and is presented in an accessible and explicit format that allows for easy practical application (Kagan, 2011; Simmons-Mackie, 2011). The framework consists of four domains that intersect and create four overlapping constructs that are integrated and influence each other:

1 **Participation** in life situations
2 Language, communication, and related **impairments**
3 Personal **identity**
4 **Environment**

Kagan observes that these overlapping constructs reflect a belief that a person's quality of life is the core and is generated by multiple domains (Kagan et al., 2008) (see Chapter 12, Figure 12.1). The emergence of this approach fulfills the call that Holland and Elman (2021) defined as the "Social Imperative" that requires involvement of the environment, consideration of cultural contexts, as well as supporting participation and well-being (Epstein & Street, 2011).

Correspondingly, a parallel process developed in the experiences of many Speech-Language Pathologists (SLPs). An example follows that illustrates this change of focus for intervention. One of the PWA receiving treatment at a medical rehabilitation center in Israel was Nurit[1], a 60-year-old woman, married with two older children. After having a stroke, she was diagnosed with severe conduction aphasia. The intervention focused on speech production and reading comprehension. Following 8 weeks of intensive treatment, Nurit had significantly improved her ability to convey functional verbal messages during therapy sessions and her SLP was excited about her progress. Her response, however, was "*I disagree with you! When I leave your room, I do not open my mouth because if I speak, everyone will think I am ignorant*". Nurit's perception of her frustration from the therapeutic process made clear the need to make a profound change in the intervention approach. The search for a new and effective treatment approach pointed to the work of Elman and colleagues (Elman & Bernstein-Ellis, 1999a, 1999b). Consequently, the first conversation group was launched at the rehabilitation department, participated in by Nurit and three other women. Following the group intervention, Nurit was able to enhance her communication skills, which in turn allowed her to gradually return to participate in more social activities. Nurit, like other PWA, completed her rehabilitation program at a medical center and returned to her community. Hence, it is imperative to develop rehabilitation centers in the community based on the LPAA model to improve PWAs' participation in society (LPAA, 2000).

The Adler Aphasia Center in Jerusalem is a community rehabilitation center for PWA in the chronic stage and their families. Thanks to the joint support of the Adler foundation and HAC the center functions as a non-profit organization within an academic setting. Students conduct part of their clinical education at the center. Including the social model in the academic and clinical education of SLP students is central to the implementation of LPAA-focused centers.

The main aim of the center is to create a supportive community to improve quality of life for PWA and their families. The center is geared toward developing an efficient and appropriate rehabilitative program tailored specifically for each person. Activities at the center are based on the social model and LPAA for intervention for PWA and focus on the person's strengths, expansion of activities, and involvement in society throughout the life span. The main activities offered at the center include individual treatment focused on LPAA goals, conversation groups, communication art groups, training communication partners, enrichment topic groups, cultural community events, advocacy for aphasia, and an extracurricular education center that educates other healthcare providers.

Education as a Force for Implementing the LPAA

Hoepner (2020) describes the LPAA framework for teaching and learning as including four domains: (1) Experiential learning, (2) Focus on learner development, (3) Emphasis on life experience, and (4) Multipronged learning context. The education program at the Department of Communication Disorders, together with the Center, applies evidence-based practice (EBP), case-based learning, reflective practice, and supervision in order for students to become effective participants in our LPAA-based center. This integrative non-medical model encompasses discipline-specific knowledge and core mental elements (Eggbeer et al., 2007).

Evidence-based practice as a standard is a core component in all clinical education programs (Gillan & Gillan, 2008) and a necessary component of effective and ethical treatment. Reflective practice and supervision involve examining with someone or independently, the thoughts, feelings, actions, and reactions evoked in the course of therapeutic work with clients. It is the context and interpersonal environment that permits self-reflection and professional use of the self after each clinical assignment. Clinicians need to learn the basic mental constructs of reflective practice: a working alliance, developing empathy, understanding the use of self, transference, and counter-transference (Geller & Foley, 2009). Among other methods of supervision, the practice of written reflections included in the program became an important manner of communication between students and supervisors, with students reporting through written reflections. There are three aspects of the reflection that determine their qualitative level: recalling or detailing, attending to feeling, and evaluating experiences that develop parallel to knowledge acquired during courses (Meilijson & Katzenberger, 2009).

Case-based learning is an integrative learning approach that provides practical experience and can lead to lifelong learning. The approach aims to strengthen a student's motivation to inquire and develop critical thinking. It seeks to integrate the contents of students' clinical education and creates an environment which encourages questions (Leahy et al., 2010). As part of this case-based approach, some students accompany a PWA, provide individual treatment, and participate in communication groups. The following is a written reflection which an SLP student presented after an intervention:

> My first challenge as a student clinician at the Adler Center was to do away with the medical model for aphasia intervention. That was the model applied at the rehabilitation department at a medical center which I was assigned previously. The social approach required that I would be focused on initiating communicative interactions and taking responsibility for mutual conversation. Supervision helped me move from the medical to the social model and strengthen the interaction by listening to Hana's mental process and my own as a clinician, that affects the flow of the conversation and the implementation of the goals. Throughout the intervention I became more empathic toward the PWA and her emotional state, and I was able to tune in with her emotionally but without identifying with her, which may have disrupted the therapeutic process.

The above self-reflection shows the huge challenge in development from a beginner clinician to one that feels comfortable implementing LPAA principles. In her reflection, the student described the educational evolution process of theoretical and experiential knowledge in addition to mental constructs that are the basis of reflective practice, such as developing empathy and the use of self.

Reciprocal Benefits of an Aphasia Center in an Academic Setting

A key aspect of the LPAA is its authentic context in the environment (Hoepner, 2020). The location of the center at the college allows for interdepartmental activities as well as the development of extracurricular educational programs. Some students participate in courses offered by the center, others receive a scholarship to work at the center, and others receive instruction in conversation accessibility with the PWA. The administrative and academic personnel at HAC are also integrated in the center's activities, enabling the development of an enriched natural and non-medical relationship for the PWA and their families.

For example, "Aphasia Café" is a round table discussion meeting that is held once a year. Meetings are led by the members (PWA), who invite students and faculty to hear their personal stories and learn about aphasia. This project ensures that new entering students are exposed and directly acquainted with the essence of living with aphasia. These meetings enable the PWA to become self-advocators (Harmon et al., 2019). Their ability to tell their stories becomes one of the ways they develop their new personal identity after the stroke. By talking to others about "who we are and what we have done", PWA were able to maintain and reconfirm a sense of identity. These social interactions can help them establish for themselves and others that regardless of aphasia they still have a past, present, and future (Swart & Horton, 2015). They experience dialogue with unfamiliar people and feel they have a part in influencing the environment of their lives.

The members of the center are encouraged to participate in conferences (for instance, the annual international conference of the MA program in the department) and share their personal experiences as PWA in lectures and panel discussions. Their participation in conferences is an opportunity for them to share their expertise and bring to the table issues that are important to them from their own experience. During one of the conferences, two members of the center, guided by their SLP, described their new identity in their families and in their community. Shadden (2005) suggested that understanding identity may be useful for improving quality of life in PWA. The opportunity to participate in an academic conference heightened their self-esteem and enabled them to reconnect by creating a sense of continuity between who they had been and who they are now (Swart & Horton, 2015). The value of the presentation is depicted well by Ely who presented in the last conference:

> My participation in the academic conference allowed me to express myself and to convey my message. I felt that I was heard and people showed interest in me. I was reinforced by the feedback I received. I felt I returned to the position I was before the stroke – a lecturer in front of a crowd.

Interdepartmental Activities that Focus on Life Participation

To encourage multidisciplinary and cross disciplinary activity between departments, the center upholds active links with other academic departments at the college, such as Inclusive Industrial Design, Photographic Communication, and Optometry. One of the joint projects with the Department of Inclusive Industrial Design was intended to study the effects of the Communication Fan (see Figure 13.1) as an AAC tool designed to support conversation between a family physician and the PWA. The rationale for the development of this tool includes ergonomic and communicative elements. Ergonomically, it was necessary to fix the size and the grip of the fan, which can be used with the left hand, to accommodate those with right hemiparesis. Communicatively, the content of the fan was designed to meet the needs of a consultation with the family physician who knows the PWA and comprises requests that are typical of a medical dialog. The tool comprises special topics such as type of complaints, referrals to specialized physicians and/or treatments, reporting and place of specific pain, and more. This project was designed as a research seminar by students and faculty from both departments.

Another joint interdepartmental project was the Design Research Course that aimed to teach Industrial Design students to generate new insights about how design research could contribute to the rehabilitation processes. All course students participated in a partner training workshop before their meeting with the Adler Aphasia Center's members. The example below describes the outcome of one of these projects.

Eyal, a 45-year-old man, married with seven children, was diagnosed with severe expressive aphasia after a head injury. A group of design students were confronted with the task of finding rehabilitative solutions for Eyal. Following his trauma, Eyal lost interest in his previous occupations, hardly communicated with his children, and spent most of his time in front of the TV. The students met Eyal at his home and found out that before his head injury he had single-handedly renovated his home and had found ingenious solutions for storage. He was proud to show them all his creative work at his home. The home visit was a turning point for the project, as the students realized that Eyal's creativity would be the key for his rehabilitation. Acknowledging his identity as a religious Jew, the

FIGURE 13.1 "Communication Fan" – A medical conversation handheld fan.

Photographer: Haim Kohl.

students created a platform for the design and production of Mezuzahs (a traditional Jewish object that is affixed to the doorpost) at his home. Eyal succeeded in producing Mezuzahs and gave gifts to his family and friends. Later the college administration ordered Mezuzahs to give as presents to the college's guests. Eyal's wife's comment to the students emphasizes the benefits of the project: "*You brought me back my husband, he is motivated and he finds meaning in his creative activity*". Creative-arts-based therapies for stroke survivors has been shown to promote social engagement (Lo et al., 2019), and this is what was observed with Eyal. Shahar and Ventura (2023) described the performance of the design students in the project as skillful and as enabling navigation between the conflicting demands of art and rehabilitation, patient and designer. In addition, they observed that the personal relationship that evolved between the students and their allocated partner proved to be a major factor in the project's success.

A third example is the Photography group, organized in collaboration with the Department of Photographic Communication and aimed to enable PWA to acquire a new mode of self-expression by utilizing their residual abilities. Lo et al. (2019) has described how photography can gradually become a tool for communication, a medium for reintegration and a part of the identity of PWA. An example of this process is described by Mira, the wife of one of the members, that remarked:

> Since he uses his camera, he approaches people on the street, he shows them his "aphasia card" and he asks permission to photograph them. In addition, he takes advantage of his non-verbal communication skills, especially his friendly smile. From this point, the encounter becomes a social event.

Photography allows members to explore their personal identity as PWA. Figures 13.2 and 13.3 describe the feelings of the photographers and their social alienation. The photographs taken by the members are exhibited in an open exhibition to the public. The fact that they are identified as artists and not seen only as persons with aphasia allows them to enhance their personal identity. Moreover, the exhibition provides their family an opportunity to regard them through a different point of view, as creative artists and not as disabled persons, as described by Thompson (2009).

Extracurricular Educational Activities

Extracurricular collaborative practice is an important aspect of education in the community. The center collaborates with the School of Medicine at the Hebrew University in Jerusalem by offering workshops to medical and nursing students about aphasia, partner training, and meetings with the members of the center and their families. Reduced communication opportunities for PWA may result in reduced participation in healthcare decision

FIGURE 13.2 Example of a photograph that expresses the photographer's feelings as a PWA. Haim named the photograph "My Aphasia" describing his social alienation.

Photographer: Haim Kohl.

making and adverse events at hospital (Hemsley et al., 2013). According to the literature, educating health care professionals is one of the reported solutions for those communication barriers (van Rijssen et al., 2022).

The Adler Aphasia Center also offers dedicated seminars for SLPs, focusing on applied aspects of the principles of the life participation approach. SLPs receive tools for implementing the LPAA model, which are adapted to the Hebrew language and to Israeli culture, for example, in Communication Partner Training (CPT). CPT has been shown to be effective in several ways: improving the communication partner's skills in supporting communication with PWA, improving the participation of PWA, and reducing the negative psychosocial consequences for partners and PWA (Simmons-Mackie et al., 2010, 2016). However, it was found that only a small percentage of SLPs apply CPT in their practice (Chang et al., 2018; Simmons-Mackie et al., 2016). Consequently, a study was designed to develop a protocol in Hebrew for working with families of PWA in Israel. The protocol was presented during seminars for SLPs and promoted for further application at other centers. In addition to the seminars, a web

FIGURE 13.3 Example of a photograph that expresses the photographer's feelings as a PWA. Avi named the photograph "My Reflection".

Photographer: Avi Israel.

forum sponsored by the center was opened to reinforce the SLPs' use of CPT and allow them to discuss issues pertaining to the integration of CPT in their clinical work. Moreover, a group of SLPs from the forum collaborated with the Israeli Speech and Language Association to write a position paper with guidelines for the role of SLPs in providing communication partner training for people with acquired communication disorders. The aim of these guidelines is to initiate change at governmental levels.

Multicultural and Multilingual Challenges and Opportunities at the Center

The multilingual character of the members of the center presents another challenge to SLPs in finding the appropriate delivery service that suits language differences. For that purpose, a communication group was started for bilingual members who speak English as their first language and Hebrew as their second language. The group is guided by an SLP whose first language is English. The bilingual members can choose to participate in either the Hebrew or the English-speaking group. Hanan, a bilingual member who arrived in Israel from Canada at age 16, had a stroke at 57 years old and was diagnosed with moderate expressive aphasia. The gap between his first (better-spared English) and second (more-impaired Hebrew) languages was prominent in his speech production. During the first years of his participation at the center, Hanan insisted on participating in Hebrew-speaking groups in spite of having better communicative performance in English. After discussing the issue with Hanan, it was decided that he should participate in the English-speaking group, and that in all other activities he would speak in English although other members and the SLPs would address him in Hebrew. While most persons with aphasia may prefer receiving therapy in their first language, immigrants often find it functionally more efficient to receive therapy in their second language (e.g., Gil & Goral, 2004). Centeno (2008) suggested that in order to understand language choice, it is necessary to consider emotional connections, ethnic identity, and communication contexts associated with each language.

Conclusion and Future Directions

The Life Participation Approach to Aphasia is officially over 20 years old (LPAA Project Group, 2000). Nevertheless, it is important to acknowledge that 50 years ago Marta Taylor Sarno published the "Functional communication approach", thus introducing the paradigm of social participation (Simmons-Mackie, 2021). While, notably, LPAA has not yet become the leading therapeutic approach for clinicians who work with PWA (Fridriksson & Hillis, 2021), establishing the center in the Communication Disorders Department at HAC was a turning point in the implementation of the social approach to intervention in Israel. According to Devanga et al. (2021), academic-based aphasia programs are a vital part of the continuum of care for aphasia. As was shown in this chapter, a strong cooperation between a community aphasia center and an academic program is one setting that can lead to an effective implementation of the LPAA principles. The underlying reciprocal benefits that derive from this integrated approach of service delivery and education can be described in the following domains:

Education

The broad LPAA perspective supported by the A-FROM allows students to develop empathy and gain insights into the lived experience of the person with aphasia. The observation of the experiences of the PWA communicating in different situations enables students, as well as the PWA, to plan goals for intervention in the most efficient way so as to enhance the quality of life of the PWA. LPAA is integrated in the academic curriculum allowing the students to make the connection between theory and practice. Addressing the lived experience of PWA is crucial for LPAA implementation (Harmon et al., 2019). The SLPs and students who participate in the center's activities become LPAA ambassadors in their communities. They advocate for further development of the social approach among health care organizations and administration. Graduates who do not necessarily continue to work with aphasia experience the important influence of the ICF and the LPAA values that are relevant to the lives of all people with communication disorders.

Integration in the Community

Simmons-Mackie (2021) describes the environment of the person with aphasia as a significant theme of the social imperative. The location of an aphasia center in a community opens a variety of opportunities for participation of PWA. The academic setting can become a supportive environment that provides positive experiences and creates a feeling of belonging that enhances wellbeing and social interactions. Armour et al. (2019) claim that one's environment includes the physical and social factors at home and in the community and can take a critical role in promoting communicational opportunities that are enjoyable and healing. We found support for this, in that members' participation in extracurricular activities such as conferences, the "Aphasia Café", and workshops allows them to integrate in their community as self-advocators.

Future Directions

The implementation of the LPAA framework has been developed successfully at the Adler Aphasia Center in Jerusalem in cooperation with the Department of Communication Disorders at HAC and it has had a great impact throughout the country. In the future, we recommend opening more centers in Communication Disorders Departments that have secured mutual cooperation. These new centers will contribute to the enhancement of the skills required for sustained implementation of LPAA and the development of new models of aphasia rehabilitation. We strongly recommend that founders of new centers choose an academic department that values collaboration with the community, as this approach is considered the best fit for a center based on the LPAA, as has been shown in this chapter.

In addition, it is recommended to strengthen financial cooperation between external funding and academic programs. Simmons-Mackie (2021) stated that “funding will be an important consideration as we embark on the next 20 years of LPAA” (p. 219). Participation of PWA and their families in an aphasia center is not supported by the medical insurance programs in Israel. The cooperation of an academic SLP program in addition to external donations may afford the economic base for permanent, long-term care for PWA. The gains of academia from collaborating with the center are substantial, in that it allows students to participate in a unique clinical practice that could not be attained otherwise. As shown, students acquire tools that are central to the development of future SLPs in the implementation of the LPAA model for working with PWA and their families. Finally, the centers may provide a supportive environment for the promotion of advocacy for lifelong intervention for PWA and their families.

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Note

1 All names of PWA mentioned in this chapter have been changed to protect their privacy.

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