

# A-FROM in Action at the Aphasia Institute

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## ABSTRACT

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Aphasia centers are in an excellent position to contribute to the broad definition of health by the World Health Organization: the ability to live life to its full potential. An expansion of this definition by the World Health Organization International Classification of Functioning, Disability and Health (ICF) forms the basis for a user-friendly and ICF-compatible framework for planning interventions that ensure maximum real-life outcome and impact for people with aphasia and their families. This article describes Living with Aphasia: Framework for Outcome Measurement and its practical application to aphasia centers in the areas of direct service, outcome measurement, and advocacy and awareness. Examples will be drawn from the Aphasia Institute in Toronto. A case will be made for all aphasia centers to use the ICF or an adaptation of it to further the work of this sector and strengthen its credibility.

**KEYWORDS:** Aphasia, aphasia centers, ICF, A-FROM, intervention

**Learning Outcomes:** As a result of this activity, the reader will be able to (1) situate the work of aphasia centers within an outcome-driven framework for intervention that is grounded in the World Health Organization's International Classification of Functioning, Disability and Health; (2) use key Living with Aphasia: Framework for Outcome Measurement (A-FROM) principles to broaden thinking about intervention and outcome; and (3) adapt illustrative A-FROM examples to his or her own setting.

The Aphasia Institute in Toronto, Canada began in Pat Arato's basement in 1979. Unwilling to accept the hopeless scenario painted by medical specialists who told her that her husband Oscar would not make any more improvement, Pat gathered a few families and volunteers together to try and turn *hopeless*

into *hope*. The current multiplicity of aphasia centers across North America and internationally, many directly or indirectly influenced by Pat's vision, is testament to what she has achieved. Many of these centers have been started by speech-language pathologists and/or family members determined to ensure ongoing

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support and growth opportunities for individuals with aphasia. Like the Aphasia Institute, many have been founded at a grassroots level with minimal funding and resources. In other cases, administrators have had to be persuaded to allow an aphasia group to be offered as a service. Pat's ideas are captured in the current vision of the Aphasia Institute—"no barriers to living successfully with aphasia." Although the vision of "no barriers" seems distant, those of us who work in aphasia centers know, based on extensive firsthand experience, that individuals and families living with aphasia can regain a meaningful quality of life (QOL) with appropriate intervention, despite the fact that language impairment has not been "cured."

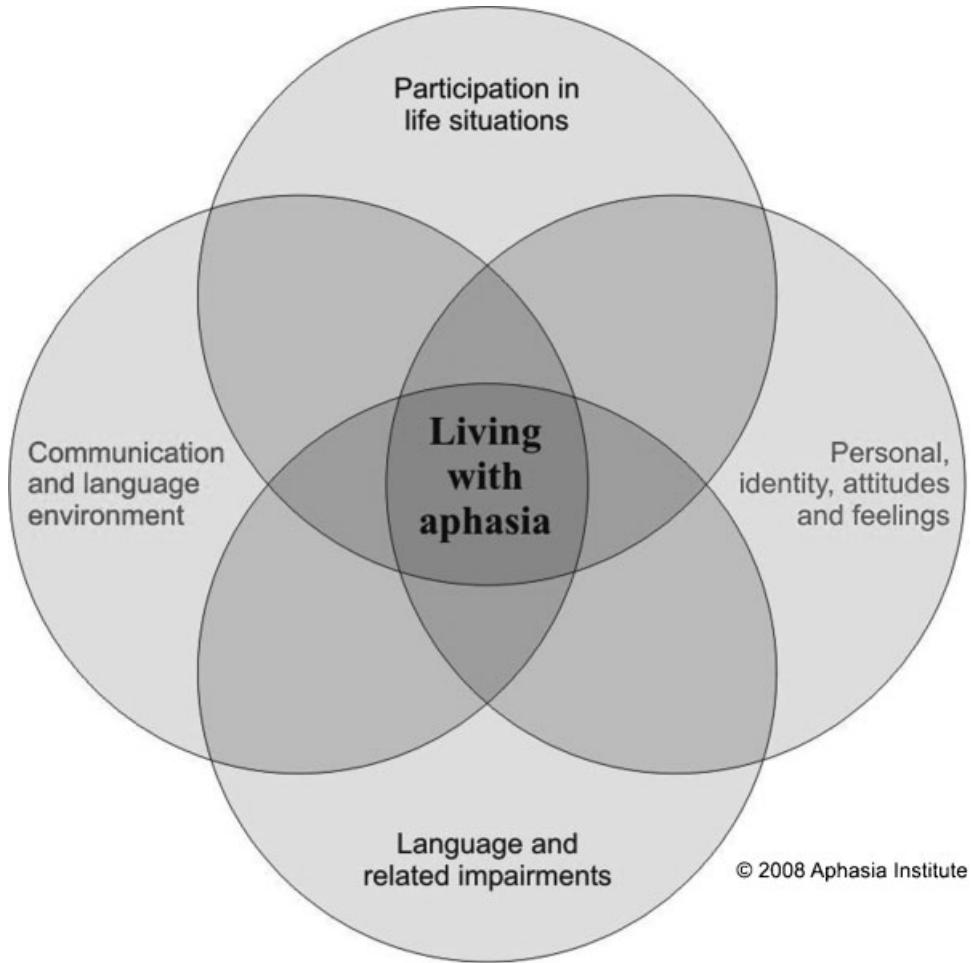
Currently, the Aphasia Institute is a teaching and learning center that operates as a synergy of direct service, education and training, and research and development. In addition to acting as an information resource, in any given year we provide direct service to over 200 people with aphasia and family members within the Greater Toronto Area. A range of direct services is offered including professionally supervised volunteer-led conversation groups, a professionally led introductory program that includes a parallel curriculum for families, exercise, various recreational and educational activities of choice, and a variety of education, training, and research programs.

As our programs have evolved over the past three decades, we have struggled with a simple method of communicating what we do to potential clients, funders, administrators, and even prospective staff members. Our solution has been the adoption of a broad, common, nonprescriptive outcome framework relevant to the real-life impact of aphasia and grounded in the International Classification of Functioning, Disability and Health (ICF).<sup>1</sup> The current article describes how this simple framework can potentially further the work of individual aphasia centers and the aphasia center sector as a whole. Applications discussed will include direct service, outcome measurement and evidence, and finally awareness and advocacy, with illustrative examples drawn from the Aphasia Institute.

## BACKGROUND TO LIVING WITH APHASIA: FRAMEWORK FOR OUTCOME MEASUREMENT

Aphasia centers offer a diverse array of programs but have a common underlying belief system regarding the potential for learning to live successfully with aphasia. Expert opinion as well as an emerging research literature suggest that this potential is reached by offering interventions that may include, but go beyond, addressing the language impairment itself—interventions that target life with aphasia.<sup>2,3</sup> Because of the nontraditional and innovative nature of this intervention, administrators, policy makers and funders are often unfamiliar with potential benefits and unclear about the rationale for our services. Therefore, to advocate for our sector or our own individual agencies, it is helpful to be able to articulate what we do and the results we achieve in a way that is clearly understandable and has credibility with decision makers. Providing a solid conceptual base for our work will help to strengthen our case for support and help plan intervention in a way that ensures outcomes with real-life impact for individuals and families living with aphasia. Living with Aphasia: Framework for Outcome Measurement (A-FROM) was developed with this in mind. A-FROM is a user-friendly version of the ICF that has been adapted for aphasia and been previously described.<sup>4</sup> In line with the values of the Life Participation Approach to Aphasia,<sup>5</sup> A-FROM captures the domains of intervention and outcome that are relevant for aphasia centers and is presented in an accessible and explicit format that allows for easy practical application. A-FROM makes an *explicit* statement about the contribution of four domains to QOL with aphasia (see Fig. 1 and Table 1). The use of overlapping circles rather than separate boxes with arrows is deliberate and suggests the real-life overlap and interaction between the four domains and overall QOL with aphasia.

Although not prescriptive in relation to specific interventions or outcome measurement methods/tools, A-FROM does emphasize the importance of focusing on outcomes relevant to living with aphasia. It provides clinicians, clients, funders, and other stakeholders with a



**Figure 1** Living with Aphasia: A Framework for Outcome Measurement (A-FROM). (Reprinted with permission from Taylor & Francis Ltd. Kagan A, Simmons-Mackie N, Rowland A, Huijbregts M, Shumway E, McEwen S, Threats T, Sharp S. Counting what counts: a framework for capturing real-life outcomes of aphasia intervention. *Aphasiology* 2007;22:258–280.<sup>4</sup>)

**Table 1 Description of A-FROM Domains**

Domain	Description
Language and related impairments	Equivalent to “impairment” in the ICF and includes traditional areas such as talking, understanding, reading, and writing
Environment	Anything outside of the person that facilitates and/or acts as a barrier to communication including individual/societal attitudes, partner attributes, physical factors, and language barriers
Participation	Actual involvement in relationships, roles, and activities of choice—situations that form part of daily life
Personal factors	Inherent characteristics of the person, feelings, emotions, attitudes, and identity or sense of self

A-FROM, Living with Aphasia: Framework for Outcome Measurement; ICF, World Health Organization International Classification of Functioning, Disability and Health.

guideline for thinking about the outcomes of various interventions. Without defining success in terms of meaningful outcomes, the definition of a successful intervention outcome can be too narrow. For example, the speech-language pathologist might work on the domain of language impairment using a neuro-linguistic treatment for writing; however, the meaningful outcome is actually change in how writing is used in daily life (participation domain) as well as related changes in areas such as motivation, sense of autonomy, and confidence (personal domain). In other words, the most critical outcomes are those of participation (relationships, roles, and activities of choice) and personal factors (feelings, attitudes, identity). Outcomes in the domains of impairment (language) and environment (communication barriers and supports including awareness, attitudes, and skills of others) are important to capture as potential enablers of participation, positive sense of self, and overall QOL.

## APPLICATIONS OF A-FROM FOR APHASIA CENTERS

### A Mandate for Our Work

In line with the broad definition of health referred to earlier, most aphasia centers include services beyond traditional language treatment. A-FROM can help to clarify for administrators, policy makers and funders the range of services and, more important, the rationale for services offered. Depending on the location of aphasia groups and centers within the overall health care system, the need for an official mandate for a broader approach to outcome measurement and/or indicators of success differs. In the case of the Aphasia Institute, a broad approach has been a *de facto* reality for many years; however, it is only recently, with the advent of A-FROM, that our board of directors has formally acknowledged its place and importance.

When the board of directors was developing the present strategic plan with the Institute staff, volunteers, and external stakeholders, A-FROM was very instrumental in

helping us understand what outcomes were relevant for the individual with aphasia. The framework kept us focused on the client as the best judge of what was “meaningful” change for them. (Quote from Jane Brenne-man Gibson, Board Chair)

Most recently, A-FROM has been officially included in our strategic plan and is currently in the process of being fully integrated into our daily operations. In addition, we now routinely use A-FROM and its compatibility with the ICF in all funding requests to the government as well as in grant applications so that decision makers can easily situate our work within something that is understandable, credible, and internationally accepted.

### Outcome Measurement and Evidence

Many speech-language pathologists would agree that our field as a whole is undervalued within the health care system. Aphasia intervention has suffered particularly in recent times with dysphagia services introduced instead of, rather than in addition to, language and communication treatment.<sup>6</sup> Within the field of clinical aphasiology itself, the advent of aphasia groups and centers focusing on outcomes that include but go far beyond language impairment is increasingly accepted and growing, but there is a large gap in the provision of evidence to support best practice. The use of a common map and terminology in measuring outcome can lead to research that facilitates evidence-based practice and that supports collaboration to benefit our entire sector.

In line with the idea of “outcome-driven practice,” this section will be followed by direct service applications rather than vice versa. In other words, clarity around desired outcome is an excellent starting point when planning intervention. The following guiding principles are useful when thinking of how to document and capture outcomes of interventions at aphasia centers<sup>4</sup> (pp. 270–271):

1. The client him- or herself is the most appropriate person for judging “meaningful” life change.

2. The client should have an opportunity to determine and choose what outcomes are relevant from his or her perspective.
3. A-FROM domains are appropriate to all aphasia severity levels.
4. Outcomes in the participation domain should relate specifically to *actual* functioning in everyday life as opposed to *capacity* to perform tasks or carry out activities.
5. Activities or tasks can be measured under the participation domain but should be understood as important components of real-life participation rather than as a separate domain.
6. A-FROM encourages multidirectional thinking and questions (for example, impact of participation intervention on impairment outcome and vice versa; reciprocal impact of outcomes in the areas of participation and personal factors).

A-FROM can be thought of as a canvas on which to track progress and evaluate effectiveness qualitatively and/or experimentally and was originally motivated by the challenge of capturing real-life outcomes frequently observed and reported by individuals with aphasia and family members participating in aphasia center programs. There are many aphasia assessment tools available depending on personal preference and purpose of the assessment. It is important to ensure that the assessment process captures the broad-based intent of aphasia

programs and that all A-FROM domains are tapped in one way or another (see Table 2). The recently developed Assessment for Living with Aphasia (ALA) covers all A-FROM domains within one tool (Simmons-Mackie N, Kagan A, Victor JC, Carling-Rowland A, Mok A, Hoch JS, Huijbregts M, Streiner D. The assessment for Living with Aphasia: Psychometric Evaluation. 2011; In submission). The Aphasia Institute will begin using the ALA as part of our intake assessment process so that we have a baseline for measuring progress. The full ALA is necessary for formal research purposes because it has established psychometric properties, but we may use selected questions for less formal outcome measurement required by some of our funders. Whatever the assessment tool used, when submitting outcome data, we have found it useful to refer to A-FROM and its direct link to the ICF, making sure that the recipient is aware of the broad range of outcome domains captured and their relevance to the lives of individuals with aphasia and their families.

### Direct Service

A-FROM can be used to capture what goes on in an aphasia center as illustrated in the following selected examples. In addition to expanding our own thinking, A-FROM helps explain the rationale for our range of services to others in a way that is easy to grasp.

**Table 2 A-FROM Domains and Sample Questions**

A-FROM Domain	Sample Question
Aphasia (language and related impairments)	How would you rate your talking/reading/writing/understanding? Overall how would you rate your communication?
Participation	Are you satisfied with the number of people you see? Do you get out as much as you want? How are you doing with your roles and responsibilities at home? Do you join in conversations at home?
Environment	Does your family know how to help you with the aphasia? Do your friends understand about aphasia—that <i>you</i> know what you want to say?
Personal	Do you feel that <i>you</i> are in charge of your life? Do you think good things about yourself? Do you have things you enjoy or look forward to?

A-FROM, Living with Aphasia: Framework for Outcome Measurement.



**Figure 2** The success cycle. (Reprinted with permission from Robbins Research International, Inc.)

### FIRST CONTACT AND INITIAL ASSESSMENT

Anthony Robbins, a world leader in the areas of business and personal development, makes reference to what he calls the “success cycle”: the importance of beliefs on perceived potential, actions taken based on this perception, and results of the actions, which in turn influence beliefs. When analyzing what we see happening when individuals and families come into the Aphasia Institute, it is helpful to use his simple diagram<sup>7</sup> (see Fig. 2) and relate it to A-FROM.

With reference to Fig. 2, we frequently see individuals and families come in to the Aphasia Institute with a fixed, often negative, belief about their communication potential and vastly decreased confidence in the ability to communicate and participate in life. In line with this, what we see is a decrease in *actual* participation as indicated in the responses to questions asked in guided conversational interviews. According to the Robbins diagram, this leads to limited results, which reinforce the belief in lack of potential, creating a negative cycle.

For many individuals and families living with aphasia, the first contact with our field involves an assessment of language impairment that highlights deficits. The obvious rationale is that this gives us, as communication specialists, a clear indication of where to begin treatment; however, such assessments likely contribute to negative beliefs about communication potential. (As an aside, language assessments are sometimes part of research conducted at the Aphasia Institute, but are not part of our initial introduction to the service.) A-FROM can be used to capture the

difference between traditional assessments and assessments at the Aphasia Institute (see Table 3).

Initial assessments at the Aphasia Institute consist of a semistructured conversation with skilled conversational support—the purpose being to assess the impact of aphasia on what clients (individuals with aphasia and family) are actually doing and feeling. One of our goals is to provide an immediate experience of success, because with conversational support, there is almost always dramatically increased opportunity to participate in conversation and exchange facts, feelings, and opinions on issues relevant to intelligent adults who find themselves living with a language impairment. During the course of this conversation, assessment staff (speech-language pathologist and social worker) obtain a clear picture of life with aphasia from the perspective of the person with aphasia and the family member. The use of Supported Conversation for Adults with Aphasia (SCA<sup>TM</sup>; Aphasia Institute, Toronto, ON)<sup>8,9</sup> techniques and sophisticated pictographic resources to ask and elicit responses to questions, ranging from simple to extremely complex and abstract, enables the people with aphasia to tell their own story. Each story is particular to the individual and his or her family member, but general themes are common and include areas such as relationships, roles, activities of choice, attitudes and skills of others, self-image, feelings, and, of course, the language impairment itself. Without asking questions in each of the A-FROM domains (see Table 2), the clinician does not have the information to discuss the broad range of options available to address the

**Table 3 A Comparison of Traditional and A-FROM-Based Aphasia Assessments**

	Impairment	Functional Tasks or Activities (Capacity in ICF)	Actual Life Participation (Performance in ICF)	Impact of Environment	Personal Factors	Overall QOL	Communication Support Provided to Maximize Success in Conversation	Explicitly Giving Hope about Potential to Live Successfully with Aphasia	Family Involvement as Client Not Only Caregiver	Explicitly Value the Perception of the Person with Aphasia
Many traditional aphasia assessments (and initial contact with the person with aphasia and family)	✓	✓								
Aphasia Institute initial contact and assessment in line with A-FROM	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Relevance: Experiencing some success in communicating and indicating that this is a service which addresses the depth and breadth of impact of aphasia appears to change beliefs about potential for positive change for the person with aphasia and the family member.  
 A-FROM: Living with Aphasia: Framework for Outcome Measurement; ICF: World Health Organization International Classification of Functioning, Disability and Health; QOL, quality of life.

impact of aphasia on daily life. Clients invariably leave the assessment feeling more optimistic about the potential for positive change. The fact that areas explored range far beyond the impairment explicitly acknowledges the depth and breadth of the impact of aphasia on daily life. In effect, by focusing on all A-FROM domains, we begin to change the client's beliefs and to expose possibilities for increased action (broad life participation). The positive results reinforce more positive beliefs, thus engaging the individual and family in what can be termed a "positive" as opposed to "negative" cycle. In other words, assessments at the Aphasia Institute are designed to highlight potential for positive growth and change and give hope in addition to identifying challenges.

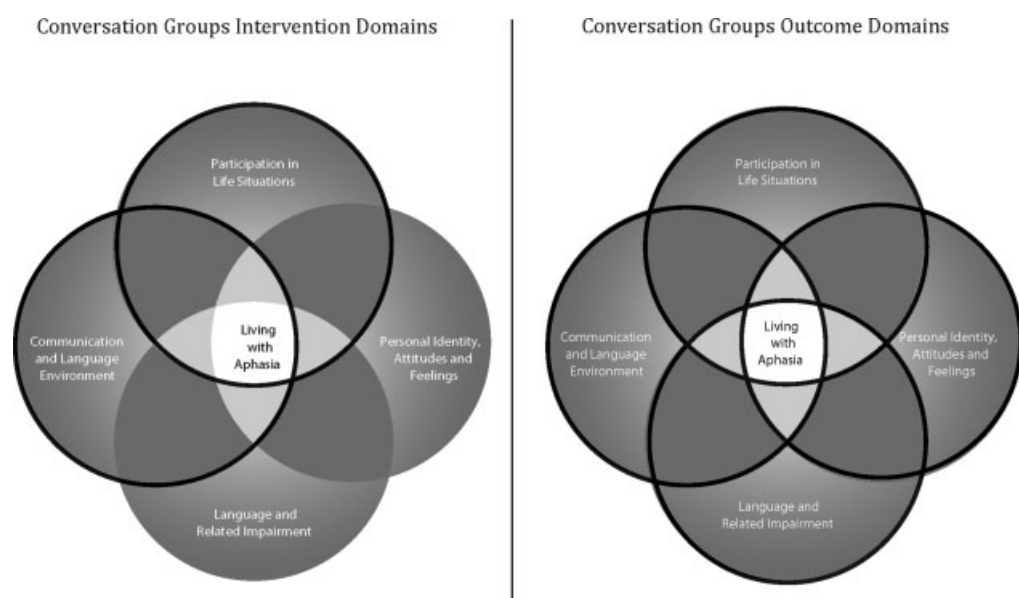
### CONVERSATION GROUPS

A second example where A-FROM can be used to clearly indicate the conceptual underpinning for our work relates to the concept of conversation groups. Although only formally named "conversation groups" in the late 1990s, these groups have been in existence at the Aphasia Institute since 1979. A-FROM can be used to clearly indicate the relevant domains of intervention and expected outcome (see Fig. 3). This provides context for studies by Elman and others<sup>10,11</sup> that provide evidence

regarding the effectiveness of conversation groups.

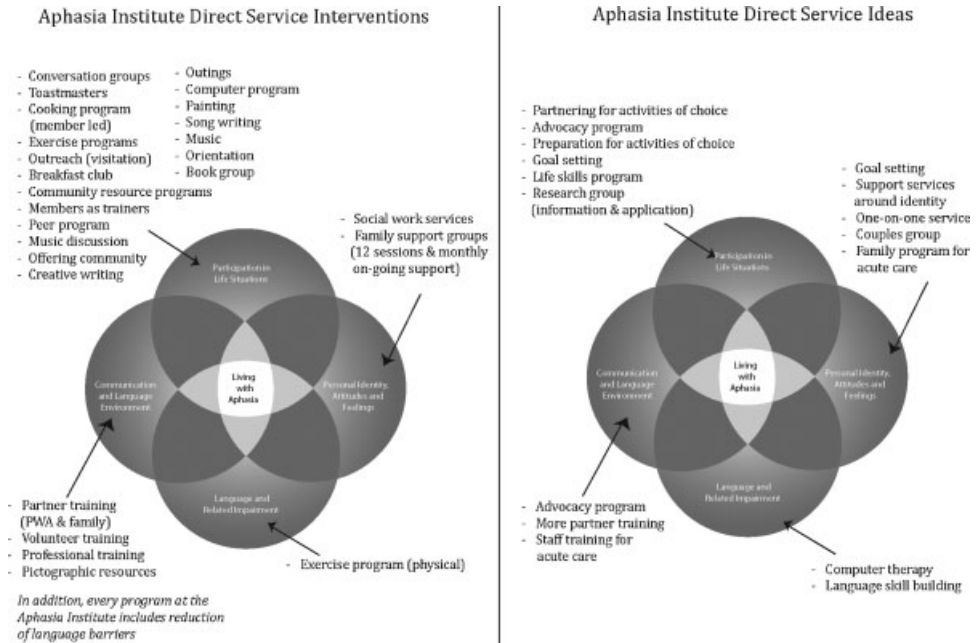
For conversation groups, participation is the major intervention domain because the activity provides actual opportunity for conversation (opportunities to establish real relationships, taking on different roles within the group, and engaging in an activity that is the most basic form of human interaction), as opposed to "preparing" clients within a context that is removed from real-life situations. Conversation groups also involve intervention in the environment domain because there is explicit focus on reducing language barriers and increasing communicative access. Thus, as with all Aphasia Institute activities, volunteer facilitators receive formal training focused on both attitudes and skill, sophisticated pictographic resources are available to get around language barriers, and the culture of the agency is one where inherent competence of people with aphasia is assumed.

Potential outcome domains, on the other hand, include all domains. Areas that can be measured include improvements in the aphasia itself (impairment), skill of the facilitator in reducing language barriers and increasing access to conversation (environment), increased confidence (personal factors), and obvious participation outcomes related to friendships, normal



**Figure 3** Conversation living groups intervention and outcome domains.





**Figure 4** Aphia Institute direct service interventions and ideas.

adult conversational roles, and enjoyment in an activity for its own sake. A-FROM is a simple way to convey these multifaceted outcomes with real-life impact to administrators, funders, and policy makers and/or others in decision-making positions.

**PROGRAM PLANNING**

In our efforts to maximize the benefits of using A-FROM as part of planning for the upcoming year, we recently asked direct service staff at the Aphia Institute to allocate every direct service we provide to individuals and families living with aphasia to the appropriate domain. We then reviewed this as a group, specifically focusing on gaps and where we might consider adding additional programs or a different mix of programs (see Fig. 4). For example, in noting interventions and outcomes per domain, staff noted that although all our activities generally contribute to *outcome* in the area of personal factors, there is a gap in range of choices related to *direct intervention*, for example, ongoing support groups and individual counseling for our clients with aphasia and for family members.

A-FROM is not being suggested as “the answer” to program planning or any other

activity. It does, though, make us consciously aware of what is implicit and often taken for granted. We found that using this framework generated enthusiastic and creative discussion. Staff thought more deliberately about how to achieve maximum outcomes in as many domains as possible for each intervention. Even the most experienced among us had new insights and ideas. This initial brainstorming session was followed by an intensive program planning day to ensure that we address all A-FROM domains to the extent possible.

**CLIENTS AS EQUAL TEAM MEMBERS IN DIRECT SERVICES**

A-FROM is available in pictographic format (see Fig. 5) and can be used to create a shared intervention and outcome agenda with individual clients and with clients as a group. It is empowering for clients to understand the rationale for various aphasia center activities. It is a means of expanding ideas on what is possible for them to achieve.

The pictographic version of A-FROM is now posted on our walls for quick reference by clients and volunteers, and it is not unusual to find a person with aphasia looking at or asking



**Figure 5** A-FROM in pictographic format. (Reprinted with permission from Taylor & Francis Ltd. Kagan A, Simmons-Mackie N, Rowland A, Huijbrechts M, Shumway E, McEwen S, Threats T, Sharp S. Counting what counts: a framework for capturing real-life outcomes of aphasia intervention. *Aphasiology* 2007;22:258–280.<sup>4</sup>)

about the schematic. The pictographic version can be used to explain intervention methods and to help clients “see” progress in domains other than impairment. This is relevant for both the person with aphasia and the family member. It is useful to do this separately for the person with aphasia and family member because, although the domains remain constant, what the domains cover and user perspective can differ. For example, family is part of the environment for the person with aphasia but the person with aphasia is part of the environment for the family member/significant other. The following actual scenarios provided by staff, illustrate the potential for direct use of A-FROM with clients.

In a recent family group during our 12-session Introductory Program, the discussion revolved around how one can measure success and that with aphasia, progress is so hard to see. We used the A-FROM schematic, which depicts the Language Impairment circle with words describing aphasia, to help make an abstract concept real and to help illustrate the importance of engaging and participating in life. The group listened and questioned, and one family member, who had been quite passive, seemed to gain a better understanding about aphasia and what he should be expecting and striving for. The following was discussed in relation to each domain:

- Language and impairments: impairment-level work is done primarily in inpatient hospital settings and rehabilitation.
- Our focus is where the circles all meet—living with aphasia.
- Our focus is QOL, and A-FROM domains are a means to think about progress and to have an opportunity to be an active participant in decisions and conversations involving the life of the person with aphasia.
- Members of the family group represent a part of the communication and language environment of the person with aphasia, and the environment is impacted by their increased knowledge, their support, and their advocacy in the bigger environment.
- Participation in life situations is greatly impacted by aphasia.
- Personal identity, attitudes, and feelings are areas of life that are diminished by aphasia and tend to be increased as individuals with aphasia are able to reengage and be involved in their lives.

A speech-language pathologist (Introductory Program Leader) said, “The information was very well received. We plan to include a discussion on this topic in future Introductory Programs for both members with aphasia and the family support group.”

A social worker (Introductory Program Leader) said, “In a one-on-one counseling session, a member was totally despondent about lack of progress in the impairment circle, repeatedly asking questions of what’s next and what the future will be. It was helpful to acknowledge that the greatest loss was in the impairment circle, and to explain that this is the work he is still doing with a private speech-language pathologist. However, the A-FROM schematic helped to expand the conversation into an examination of progress already made and the richness of the possibilities in the future.”

## **AWARENESS AND ADVOCACY**

We are currently using A-FROM as an essential element of our aphasia advocacy campaign, specifically to increase awareness and knowledge of aphasia. As we know,<sup>12,13</sup> this is needed

not only for the general public but for the health care community members, who need to see themselves as part of the environment for people with aphasia. For example, we recently worked with a graphic artist to create online “living A-FROMs” as we chatted to health care policy makers, administrators, researchers, and frontline staff at an Innovations Expo held in Ontario and attended by the Minister of Health, who visited our booth. We had extremely limited time to get complex concepts across and found A-FROM helpful in doing so as it is an instantaneous and obvious snapshot of key challenges related to aphasia.

Awareness and advocacy are as important within an aphasia organization as outside of it. A recent survey asking staff at the Aphasia Institute about A-FROM and their own use of it internally and externally elicited some of the following comments:

The visual schematic is helpful in explaining the abstract work we do and also highlights the systems theory factors in our work. (Clinical staff)

Since we cannot be experts in all areas, it helps me determine where we fit and how we contribute to the other domains. (Clinical staff)

When I speak to people about what I do, after we get through what aphasia is, inevitably the conversation turns to how we help people speak. I then say that we don’t actually do that kind of therapy, but that we help people live with their new situation. Although I don’t specifically say A-FROM, I do say that speaking is one part of a whole person, and there exists other areas that we help work on, so people can return to living a full and complete life, albeit with aphasia. (Administrative staff)

User-friendly for a lay audience . . . and not dependent on professional jargon. (Clinical staff)

It helps me identify areas that I need to work on: counseling of clients and families or getting familiar with medical terminology when going through a referral form. (Clinical staff)

Over the past month, we have been looking at A-FROM with the volunteers. We took the time to break up each domain and understand what fits into each as well as how they overlap. In subsequent weeks, following the larger presentation on A-FROM, prior to each presentation we looked at A-FROM and reminded ourselves where the topic fit in and to remember how it can impact all other areas as well. . . . I think it helped the volunteers understand our members more deeply and see the entire person as well as the numerous barriers they face. It was great to see how excited the volunteers got, especially when discussing the environmental factors and how we can be doing so much more to advocate, etc. It was also good to look at ourselves and see what things in our environment help or add barriers to our members. (Clinical staff)

Also useful to orient new staff, visitors, and stake holders to our “common language.” (Clinical staff)

Enabling those living with aphasia to act as advocates for themselves is another element of the advocacy process as illustrated in the following poignant example captured in a session where staff used A-FROM as a platform to “interpret” client stories for volunteers in a way that enabled them to clearly identify areas of intervention and outcome. After partner training, the wife of a terminally ill client with aphasia used SCA (environmental intervention) to convince doctors that her husband did not want his life prolonged with additional interventions. Despite the sad ending to the story, she felt good about the fact that he was able to exercise autonomy (personal factors outcome) and fully engage in decisions about his own health care (participation outcome).

## CONCLUSION

In conclusion, we suggest that aphasia centers will find it helpful to use the ICF and/or A-FROM to further develop thinking; as part of work on increasing awareness; and as a framework for collecting data that will help others to

help us in our efforts to make living successfully with aphasia a reality for as many people as possible.

## ACKNOWLEDGMENTS

This article is the result of many conversations with staff, volunteers, and clients at the Aphasia Institute and is written in tribute to them all. In addition, the author thanks Dr. Nina Simmons-Mackie for her insightful comments on an early version of this article.

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