

Counting what counts: A framework for capturing real-life outcomes of aphasia intervention

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Background: The initial motivation was our inability to capture the important but often elusive outcomes of interventions that focus on making a difference to the everyday experience of individuals with aphasia and their families. In addition, a review of the literature and input from stakeholder focus groups revealed the lack of an integrated approach to outcome evaluation across diverse approaches to aphasia intervention. Input from focus groups also indicated that existing classifications and models offering potential solutions are not always easily accessible and user friendly.

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Aims: We aimed to create a user-friendly conceptual framework for outcome measurement in aphasia that included a focus on real-life outcomes of intervention and could be easily accessed by clinicians, researchers, policy makers, funders, and those living with aphasia. We wanted to build on existing work, e.g., that of the World Health Organisation, simplify presentation for accessibility, and make specific adaptations relevant to aphasia. By providing a common context for a broad range of outcome tools or measures, we hoped to enable more efficient and effective communication between and among all stakeholders.

Main contribution: *Living with Aphasia: Framework for Outcome Measurement (A-FROM)* is a conceptual guide to outcome assessment in aphasia that is situated within current thinking about health and disability. This simple platform can be used to frame and broaden thinking concerning outcome measurement for aphasia clinicians and researchers while enhancing the potential for meaningful communication between the clinical community, policy makers, and funders. By integrating Quality of Life and including domains related to environment, participation, and personal identity in the same framework as impairment, the importance of outcomes in all these areas is acknowledged for aphasia in particular and disability in general. A-FROM has the potential to be used as an advocacy tool.

Conclusions: This article is the first presentation of A-FROM as an alternate guide to outcome measurement in aphasia. Initial ideas regarding applications are discussed. Further development and applications await input from our community of practice.

As the scope of intervention in aphasia has broadened in past decades, we see dynamic changes occurring in the lives of people with aphasia and their families who have received our services—changes in areas such as self-image, hope, confidence, motivation, attitudes, and ability to participate in conversation, functional tasks, and valued activities. These changes can occur in addition to, or despite, a lack of significant change in impairment status. *Living with Aphasia: Framework for Outcome Measurement (A-FROM)* is a broad, non-prescriptive conceptual approach to outcome measurement that takes account of the impact of aphasia on life areas deemed important by people with aphasia and their families. The A-FROM project was motivated by the challenge of capturing, documenting, and tracking real-life, meaningful changes in individuals affected by aphasia in order to help organise outcome evaluation, as well as aid in designing advocacy efforts and research regarding the effectiveness of interventions. By creating a framework that makes equal sense to all stakeholders, including those affected by aphasia, clinicians, researchers, policy makers, and funders, we hoped to enable more efficient and effective communication and provide a common context for a broad range of outcome tools or measures.

Impetus for the project came from our frustration with current approaches to outcome measurement in aphasia. For example, we subjectively observed marked changes in confidence and social participation after intervention, and recipients of our service associated these changes with the aphasia programme. Yet we failed to capture these outcomes, since participation in community life and psychosocial characteristics (e.g., confidence) have not routinely been part of aphasia assessment. We felt that evidence of these changes would provide additional support for the worth of our services and help us to better focus our intervention in the future.

Stakeholders such as clinicians, consumers, funders, and policy makers want evidence of a range of meaningful life outcomes associated with treatment. However, in spite of a call for more accountability in the realm of functional outcomes and life

participation (Simmons-Mackie, Threats, & Kagan, 2005), many aphasia clinicians continue to measure relatively narrow, behaviourally defined, discrete performances such as ability to name 10 common objects, follow one-step commands, or point to pictured items. Measurement of broad and diffuse outcomes such as quality of life or social participation is far less prevalent. Also, when measurement tends to focus on discrete language tasks or tests, then intervention tends to follow suit. Thus, less attention is afforded to the realms of communication participation, psychosocial status, and quality of life. We felt that the ability to capture a range of meaningful outcomes was stymied by the focus on linguistic impairment and narrow tasks.

Another source of frustration has been the huge selection of available tools to measure outcomes in aphasia. These tools draw from a wide range of theoretical orientations and sample a confusing array of behaviours. Clinicians face a daunting task when they try to choose which measures are most appropriate for a given client. In fact, studies have demonstrated significant variability in the outcome assessment practices and specific outcomes measured by speech-language pathologists (Hesketh & Hopcutt, 1997; Simmons-Mackie et al., 2005; Worrall & Egan, 2001). Also, existing tools tend to produce data that are segregated. That is, assessments across domains (e.g., language tests, functional communication assessments, psychosocial measures, cognitive assessments) have not been tied to a common and coherent conceptual system. A perplexing and disparate assortment of scores or results can emerge when outcome data are collected with a variety of tools. In other words, a significant problem in measuring outcome in aphasia and providing convincing evidence of meaningful life change after intervention has been the failure to employ a unifying structure that would allow clinicians and researchers to compare results, identify relationships, and visualise a range of “big picture” outcomes of importance to all stakeholders.

In order to aid clinicians in their quest to capture meaningful outcomes in aphasia, a growing literature urges the value of adopting an umbrella framework to guide documentation of outcomes related to intervention (e.g., Holland & Thompson, 1998). The World Health Organisation *International Classification of Functioning, Disability and Health* (ICF) (World Health Organisation, 2001) has been touted as appropriate (Threats & Worrall, 2004). Other useful frameworks and assessment applications have been described (Desrosiers, Noreau, Rochette, Bravo, & Boutin, 2002; Fougeyrollas et al., 1998; Garcia et al., 2003; Noreau et al., 2004; Noreau, Fougeyrollas, & Vincent, 2002). However, these organising frameworks do not seem to be reflected in routine assessment practices for a variety of reasons (Simmons-Mackie et al., 2005). For example, the ICF is complicated and cumbersome. It consists of many domains, categories, and subcategories that can be confusing for clinicians to negotiate. With very few exceptions (e.g., Garcia et al., 2003), we found little formal work *explicitly* applying broad frameworks such as ICF to the specific language barriers of people with aphasia. In fact, Worrall and Cruice (2005 p. 888) argue that most of the work relating to domains beyond linguistic impairment “occur outside the field of aphasiology ...”. In addition, there are an overwhelming number of potential categories to measure within the domains of generic frameworks and models—categories that are important, but might not be directly relevant for our purposes. For example, outcomes in the area of mobility or dressing are not typically influenced by treatment of aphasia. We felt that a usable organising system should directly reflect aspects of life closely related to living with

aphasia. Therefore, a simple, user-friendly conceptual outline was needed to help organise outcome measurement in aphasia and provide a common “language” for all stakeholders.

DEVELOPMENT OF A FRAMEWORK

In order to address the needs and challenges described above, we embarked on a project to develop a simple, unified, broad, and non-prescriptive framework for outcome measurement in aphasia that would be easily accessible to clinicians while facilitating communication between clinicians, researchers, and policy makers. We chose to build on and make some modifications to existing approaches.

Values-based approaches

First, we built on values-based approaches within our field—for example, the values set forth in the Life Participation Approach to Aphasia (LPAA Project Group, 2001). This statement of philosophy for assessment, intervention, and research places the long-term, real-life needs of the person with aphasia and his/her family at the forefront. Similar values are represented in social model philosophies described by Byng and others (Byng & Duchan, 2005; Byng, Pound, & Parr, 2000; Sarno, 1993, 2004; Simmons-Mackie, 2000, 2001). Based on these values, we believe that those affected by aphasia, including families and other stakeholders, should have a say in development and implementation of a framework. These aphasia-specific, values-based approaches also highlight topics such as participation and the impact of the environment—elements integral to the broader approaches described below.

Existing frameworks or models

We also built on sources outside the field of aphasia—primarily the World Health Organisation’s *International Classification of Functioning, Disability and Health* (ICF) (World Health Organisation, 2001) and also the Disability Creation Process (DCP) (Noreau et al., 2002).

The ICF is a framework for conceptualising health and the consequences of disease (World Health Organisation, 2001). The ICF includes three major domains: body structure and function, activities and participation, and contextual factors (including environmental and personal factors). These major domains are subdivided into multiple categories. For example, activities and participation includes categories such as “communication”, “mobility”, and “community, social and civic life”. Each category is further divided into subcategories. For example, three of the subcategories subsumed under “community, social and civic life” are: “recreation and leisure”, “political life”, and “religion and spirituality”. In addition, the ICF provides a system for coding and scoring an individual across these categories.

While we found the ICF too broad to serve as a specific guide to outcome assessment in aphasia, we felt that it offered a variety of strengths upon which we could build an adapted version. The ICF has the advantage of input from an international team. These extensive international efforts have resulted in operationalisation of concepts and categories that comprise the framework. Additionally, the coding and scoring system cover a vast array of health and disability areas. The ICF

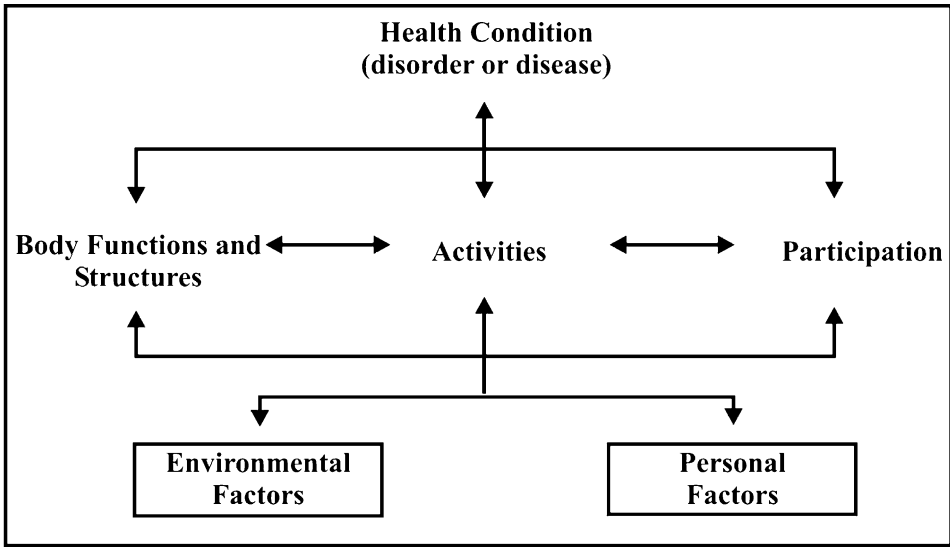


Figure 1. ICF schematic Reprinted with permission from: the International Classification of Functioning, Disability and Health (ICF), World Health Organization, 2001.

has succeeded in expanding the realm of health and health care. For example, the domains of social participation and environmental influences are now considered important elements in understanding the consequences of disease and the effects of interventions. The schematic in Figure 1 illustrates key ICF concepts.

The ICF has had significant positive influences on health care and rehabilitation, but has met with some criticism. For example, although the authors of the ICF acknowledge the integration of components, ideas are frequently presented in a linear, box-like manner that does not fully capture integration and overlap (as in Figure 1). Some (e.g., Penn, 2005) feel that the box-like framing may actually restrict rather than broaden thinking. In addition, as noted above, the ICF can be cumbersome and confusing to negotiate. For example, in Table 1 (World Health Organisation, 2001), activities and participation are included as one category; this contrasts with the separate presentation of these concepts in the schematic in Figure 1. Understanding the ICF domains and categories, and negotiating the ICF coding system, is challenging due to its complexity. Early focus groups conducted as part of our project suggested that clinicians did not readily understand the ICF. Finally, the ICF does not include the concept of quality of life within its scope; thus, it is difficult to reconcile measures of well-being or life quality with ICF.

Despite criticisms, the ICF has been instrumental in reorienting health care from a narrow medical model towards a biopsychosocial model of health and medicine. Furthermore, the ICF has been adopted by many agencies and organisations (e.g., ASHA has incorporated the ICF into best practice guidelines) (American Speech-Language-Hearing Association, 2001). Thus, we chose to make A-FROM compatible with the ICF. We also incorporated concepts from other allied models describing health and disability such as the Canadian Disability Creation Process model (DCP). DCP is a theoretical model that explains and focuses specifically on the social construction of disability and impact on participation or “life habits”

TABLE 1
An overview of ICF

	Part I: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers / hindrances	not applicable
	Disability			

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(Noreau et al., 2002). The dynamic integration of factors is highlighted in this model (see Figure 2). The DCP concepts have been translated into an application called Life-H (Life Habits) (Noreau et al., 2002) including a scoring system for rating disabilities.

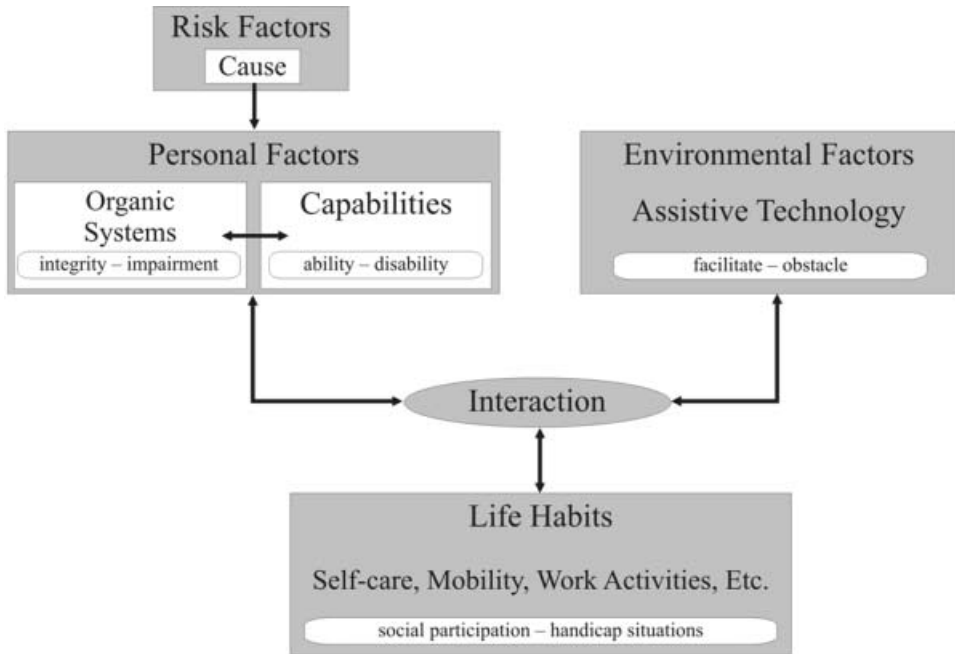


Figure 2. DCP Schematic Reprinted with permission from: Noreau, L., Fougeyrollas, P. & Vincent, C. (2002). The LIFE-H: Assessment of the quality of social participation. *Technology and Disability 14*, 113–118.

Moving beyond existing frameworks and models

As we studied the literature we were convinced that an adaptation of existing models could help to focus outcome assessment in aphasia and provide a common language for reporting outcomes across stakeholder groups. We asked ourselves, “What evidence really counts in relation to living with aphasia and how can we make the system for collecting and evaluating such evidence simple and useful for all stakeholders?” The result, *Living with Aphasia: Framework for Outcome Measurement (A-FROM)*, explicitly incorporates the impact of language and communication disability associated with aphasia. The goal was to find a way to capture and represent outcomes of aphasia intervention related to living with aphasia in a dynamic manner, without being prescriptive about interventions or measures for outcome assessment. The idea was to highlight a few major concepts so that, at a broad level, there is increased clarity and agreement for work that occurs within and across these conceptual domains and categories. It is unlikely and probably not desirable to have prescribed uniformity in details of application (i.e., actual outcome measurement tools). However, in our view, it is desirable to have uniformity and commonality at the broad level to enable more efficient and effective communication between those affected by aphasia, clinicians, researchers, policy makers, and funders. Some of the disagreement reflected in Ross and Wertz’s recent Aphasiology Forum on the ICF is a reaction to the lead authors’ call for uniformity at a narrower level (Ross & Wertz, 2005).

Methodology for development of A-FROM

The A-FROM project began by drawing on current models or classifications (e.g., ICF), current literature, our own experience, and that of our colleagues who work with individuals with aphasia and their families. In particular, the project was grounded in the needs and opinions expressed by various stakeholder groups. That is, focus groups were conducted throughout the project to develop ideas and provide feedback as ideas evolved. Focus group participants were people with aphasia (including separate groups for mild, moderate, and severe aphasia), families, speech-language pathologists, and related rehabilitation professionals. The focus group discussions were recorded and transcribed and main themes extracted from the transcriptions. Based on focus group input, initial ideas were revised and additional input was sought. Thus, the process of A-FROM development was cyclical and participatory. For example, initial focus groups involved discussions of various topics as well as key concepts from ICF (including a presentation of the components of the ICF in their original format), sample schematics, and opinions about areas most important to capture as outcomes. Based on this process the project team began to develop A-FROM.

Our experiences with early focus groups supported the need for a simple, user-friendly conceptual structure for organising outcomes in aphasia. For example, focus group participants found it challenging to understand the ICF in its published form (World Health Organisation, 2001). Additionally, clinicians reported challenges in translating the ICF into daily practices in outcome assessment. Thus, the need for a framework for outcome measurement in aphasia that could be more easily understood within the larger context and, at the same time, be compatible with widely accepted models was substantiated during the development process.

RESULTS

Living with Aphasia: Framework for Outcome Measurement (A-FROM) is the result of 2 years of focus groups and project meetings aimed at developing a simple umbrella model to organise outcomes in aphasia. A-FROM is represented at the broadest level in a “snapshot” schematic that depicts key outcome domains of interest (see Figure 3). The snapshot domains include:

- aphasia severity (correlate of ICF body function/impairment);
- participation/life habits;
- personal factors including identity and emotions; and
- environment.

These snapshot domains overlap in the centre of the schematic to create:

- “living with aphasia”—a concept reminiscent of quality of life, but focused specifically on life with aphasia.

These overlapping domains encompass the broad outcomes of importance to people affected by aphasia, clinicians, funders, and policy makers. The reader will recognise familiar concepts drawn from ICF. For example, the A-FROM domain of *Aphasia Severity* is consistent with the ICF definition of impairment of body function—an impairment or loss in “physiological functions of body systems” (World Health

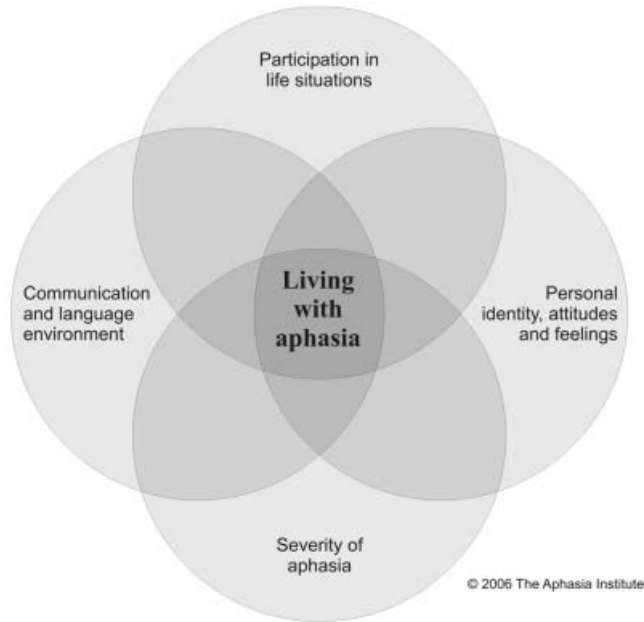


Figure 3. Living with Aphasia: Framework for Outcome Measurement (A-FROM). Reprinted with the permission of The Aphasia Institute.

Organisation, 2001, p.10). Thus, the A-FROM domain of aphasia severity encompasses measures of cognitive and linguistic processing, performance, or impairment. The A-FROM definition of *Participation* conforms to the ICF definition “involvement in a life situation” (World Health Organisation, 2001, p. 10), and includes the DCP concept of “life habits”. Activities, defined in the ICF as “the execution of a task or action by an individual” (World Health Organisation, 2001, p.10), have been acknowledged but subsumed under participation in A-FROM since most tasks are components of a larger life habit or social situation. The “contextual factors” of ICF have been separated into two distinct domains: *Environment* and *Personal* factors. Environment is defined as it is in ICF: “the physical, social and attitudinal environment in which people live and conduct their lives” (World Health Organisation, 2001, p. 10). However, based on feedback from client and family focus groups, the definition of personal factors was expanded from the original ICF factor. Personal factors in ICF include inherent characteristics of the person such as race and gender. Currently personal factors are not included in ICF coding. In the A-FROM schematic personal factors have been highlighted and expanded to include aspects of feelings and personal identity that might change as a consequence of aphasia intervention.¹ Thus, personal factors are given equal emphasis within A-FROM. The family and client focus groups felt strongly that these elements must be prominently represented in any model of outcomes.

¹The ICF includes functions such as optimism and confidence under the category of “mental functions” in body function. We have extracted aspects of feelings and identity and included these under personal factors.

A-FROM indicates our interest in finding a way for clinicians across the continuum of care, and with differing foci of intervention, to have a common approach for assessing outcome even if only using a portion of the framework. We also felt that being able to clearly situate A-FROM in current thinking (e.g., ICF concepts) gives it greater credibility with administrators, funders, and policy makers.

Although A-FROM draws heavily from existing models and definitions, key improvements should be noted. For example the A-FROM schematic (Figure 3) represents life domains (i.e., aphasia severity, participation, environment, personal factors) in circles that are visibly interconnected and overlapping rather than depicting domains with boxes and arrows as in ICF and DCP (Figures 1 and 2). Thus, key concepts are more visible and the dynamic interaction of life domains is highlighted. At the centre of the schematic the overlapping circles intersect to create “life with aphasia”. This reflects a belief that a person’s life and quality of life are at the centre of and created by multiple overlapping domains. Furthermore, the inclusion of “life” or “quality of life” at the centre of the A-FROM schematic adds an important dimension that is not readily captured in the ICF and DCP schematics. In fact, the authors of the ICF suggested in 2001 that work was needed to “establish links with quality-of-life concepts and the measurement of subjective well-being”(World Health Organisation, 2001, p.251). A-FROM provides such a link between ICF domains and quality of life.

In addition, A-FROM simplifies ICF concepts by narrowing the focus to elements of practical interest in aphasia. Thus, the ICF domain of body structure and function is narrowed to *aphasia severity*, encompassing categories such as reading, writing, speaking, and understanding. Body structure, such as the brain, is not explicit in A-FROM since structural or functional changes in the brain are currently not within the routine outcome assessment sphere of aphasia clinicians. This does not mean that measures of brain structure or function would be ignored. On the contrary, A-FROM would provide a way to organise research into the relationships between functional changes in the brain and meaningful changes across domains such as aphasia severity, participation, or personal/emotional adjustment. Another simplification in A-FROM relates to the participation and activities domain of ICF. The WHO has faced arguments about the difference between “activities” and “participation” and found that actions of people in their daily lives could not be reliably separated discretely into activities versus participation (Threats, personal communication). Rather, there appears to be a continuum from narrow discrete activities or tasks such as writing cheques or reading bills to increasingly broad life habits such as doing one’s banking or managing finances. Rather than attempt to force the issue, we chose to define the broad A-FROM snapshot in terms of broad life habits and subsume functional tasks or activities within the participation snapshot domain. That is, we assume tasks and activities to be components of larger life situations. These efforts to streamline domains and focus explicitly on aphasia result in a more simple and user-friendly framework. While A-FROM categories are clearly not exhaustive, we have attempted to represent the categories most relevant to living with aphasia and most likely to be assessed by speech-language pathologists as outcomes of aphasia intervention. This does not imply that changes in elements not explicitly included in A-FROM are unimportant; rather, we hoped to create a practical and simple guide for outcome assessment in daily practice.

Groups of people with aphasia, family members, and clinicians consistently found the A-FROM “circles” to be more easily understood than tables or linear diagrams. For clinicians in our focus groups, this simple schematic helped to visibly organise the array of potential outcomes from intervention or targets for intervention. Thus, clinicians quickly recognised that they might focus treatment within one snapshot domain such as aphasia severity (e.g., syntax therapy) and assess outcomes within this domain (e.g., sentence production) as is traditionally done, and/or might assess outcomes in other domains such as quality of life (the intersect in the middle of the circles) or participation (e.g., conversing with friends). Use of the A-FROM schematic has also facilitated the grasp of complex concepts and allowed us to make these more easily explicit to our stakeholders. For example, feedback from the Aphasia Institute Board of Directors indicated that A-FROM helped them to truly grasp the fact that the Aphasia Institute intervenes in the domains of participation, environment, and personal factors and is interested in outcome in all domains, including the severity of aphasia. Thus, the previously confusing role of our speech-language pathologists in training family members and teaching supported communication methods across our community became quite clear when we pinpointed this work to improving the domain of communicative *environment*. A-FROM also provided a format for communicating with people with aphasia about goals and expected outcomes. An aphasia-friendly version of the schematic (see Figure 4) was developed to engage people with aphasia in discussions about potential areas for intervention and where they might be looking for change.

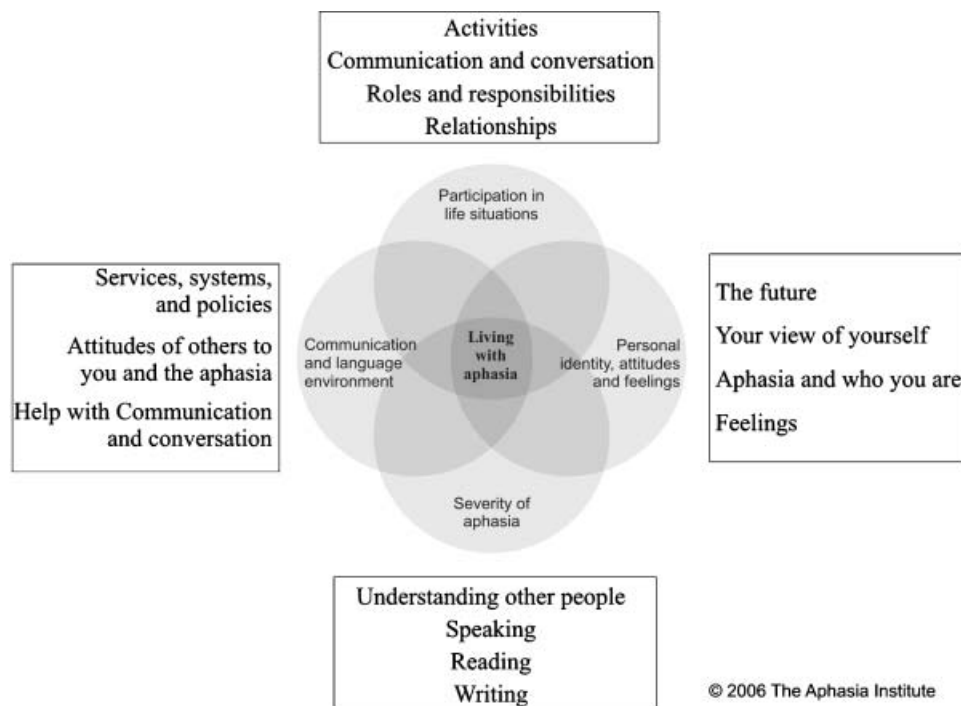


Figure 4. Pictographic version of A-FROM. From the ALA manual, 2006, reprinted with the permission of the Aphasia Institute.

Exploding the domains: Increasing specificity of outcomes

The snapshot domains depicted in Figures 3 and 4 are designed to represent the broad, diffuse realms of life that are important to people with aphasia and other stakeholders. However, outcome measures cannot be limited to capturing a broad “score” within each of these domains; goals are usually more detailed and individual. Therefore, the snapshot domains can be “exploded” into increasingly specific categories giving the user the ability to focus at the global level or progressively narrower levels depending on needs (see Figure 5). The broad levels provide the conceptual framing, while narrower levels focus on individualised outcomes with increasing specificity. For example, the broad snapshot domain of participation is composed of more focused categories such as “relationships” or “conversation”. However, categories can be further exploded into more specific subcategories such as “conversation with one person” or “conversation in groups”. Although we do not offer detail beyond the snapshot domains and exploded categories, A-FROM, as with ICF, is compatible with additional levels of subcategories or detail.

In determining the categories in Figure 5 we reviewed existing conceptual approaches and outcome measures, brainstormed based on our own experiences, and elicited input from focus group participants. We sorted and collapsed similar categories, obtained additional input from stakeholders, eliminated categories, and reconfigured categories to reflect feedback, and also to make the choices as simple and relevant as possible. During the process of A-FROM development, we began to develop an application of A-FROM, a tool for capturing real-life outcomes in



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Figure 5. A-FROM categories within snapshot domains. Reprinted with the permission of The Aphasia Institute.

aphasia. As we worked on the tool and piloted questions, the results fed back into our framework development and aided the choice of categories. Thus, Figure 5 represents one step towards more detailed outcomes. Those who use A-FROM to guide outcome measurement will certainly develop increasingly detailed subcategories and tasks that suit individual goals and interventions.

Distinguishing A-FROM from applications of A-FROM

A-FROM is an organising structure for identifying domains and categories of importance in outcome measurement for aphasia. A-FROM is *not* an outcome measure itself. Outcome measurement tools can be developed to conform to the A-FROM domains or existing tests or tools can be interpreted in terms of A-FROM domains. For example, the *Western Aphasia Battery* (Kertesz, 1982) provides a sampling of language skills that fit into the A-FROM domain of aphasia severity. The *Affect Balance Scale* (Bradburn, 1969) measures positive and negative feelings and would help sample outcomes in the A-FROM domain of personal identity and emotions. Although A-FROM does not dictate specific measurement tools or applications, several values and concepts are important.

Underlying values and key concepts to bear in mind when applying A-FROM

As previously mentioned, A-FROM evolved from a variety of sources including input from people with aphasia and their families. The following values and key concepts emerged during the development of A-FROM and provide important principles to consider when choosing or devising tools for outcome measurement.

The client him/herself is the most appropriate person for judging “meaningful” life change. Although A-FROM can encompass multiple assessment perspectives (e.g., clinician ratings or scores, family observation), the perspective of the client cannot be overlooked. Studies of patient-reported outcomes of meaningful changes or quality of life have often excluded individuals with severe aphasia or used “proxies” to judge changes. Research questions the validity of “proxy reports” in some areas since they do not necessarily agree with “patient reports” (Cruice, Worrall, Hickson, & Murison, 2005; Duncan et al., 2002). In fact, the use of patient-reported outcomes has been recommended by policy makers and funding sources. Therefore, applications of A-FROM should encompass measures that capture client perspectives, particularly as they relate to participation, personal factors, and quality of life.

The client should have an opportunity to determine and choose what outcomes are relevant from his/her perspective. The A-FROM snapshot domains are defined in terms of meaningful elements of life with aphasia; therefore, outcomes that are relevant and important to the individual should be a focus of outcome measurement. It is not particularly useful to have a client report on items or complete a test on items that are not relevant to the client’s life. For example, summary scores on functional batteries might not adequately capture “meaningful” changes to the person if multiple items are deemed irrelevant to the individual’s daily life.

A-FROM domains are appropriate to all aphasia severity levels. In order to access client perspectives, tools that involve self-report should be aphasia friendly and communicatively accessible to all clients with aphasia, including very severe aphasia.

Applications need not be limited to assessment of the person with aphasia. Consequences of aphasia on a family member or significant other are equally valid targets of measurement. Thus, the A-FROM schematic can be used to plan assessment of both the person with aphasia and other people in the person's life. For example, spouses of people with aphasia report changes in their own participation or life habits and emotional life and identity.

A-FROM is not prescriptive in relation to either intervention or outcome measurement. A-FROM is intended to help guide or situate thinking and highlight outcome domains that have not traditionally received much attention, such as the communication environment. A-FROM can be used as a guide for measuring real-life outcomes of any aphasia intervention in any setting. Within A-FROM, the clinician can identify the particular domain targeted during intervention and determine which domains and categories are of interest for assessing outcome. Specific categories within a domain might be the focus of intervention, while outcome is captured in the broader "snapshot" domain. Likewise, A-FROM is not designed to be prescriptive in relation to the particular tools or measures used to capture data. Thus, options for measuring outcomes include creating original applications using A-FROM as a platform (see, for example, the *Assessment for Living with Aphasia* in 'Potential uses for A-FROM'), or using other existing tools that are compatible with A-FROM (see, for example, Table 2 which demonstrates an array of existing assessment tools by A-FROM domain along with potential

TABLE 2

Example of measurement and intervention within the A-FROM model using existing tools. Note: Central to the use of A-FROM as an underlying platform is the notion of interaction within and across domains. Thus, with reference to the table below, one might want to assess outcome of any one of the intervention examples in more than just the intervention domain.

<i>A-FROM Domain</i>	<i>Initial Assessment Tools</i>	<i>Intervention Targets</i>	<i>Outcome Assessment Tools</i>
Aphasia Severity	<i>Western Aphasia Battery</i> ¹	Word-finding therapy focusing on strategies within a conversational context	<i>Western Aphasia Battery</i> ¹
Participation	<i>Interview (self-report)</i> <i>ASHA-FACS</i> ²	Group Conversation Therapy	<i>Interview (self-report)</i> <i>ASHA-FACS</i> ²
Environment	<i>CHIEF</i> ³	Communication Partner Training	<i>CHIEF</i> ³
Personal	<i>BOSS Communication-Associated Psychological Distress (BOSS CAPD)</i> ⁴	Life Coaching & Counseling	<i>BOSS Communication-Associated Psychological Distress (BOSS CAPD)</i> ⁴
Life with Aphasia	<i>SAQOL-39</i> ⁵ <i>BOSS</i> ⁶		<i>SAQOL-39</i> ⁵ <i>BOSS</i> ⁶

¹Kertesz, 1982; ²Frattali, Thompson, Holland, Wohl, & Ferketic, 1995; ³Craig Hospital Inventory of Environmental Factors; ⁴Doyle, McNeil, & Hula, 2003; ⁵Hilari, Byng, Lamping, & Smith, 2003; ⁶Doyle et al., 2003

intervention targets for a hypothetical client). The ICF offers similar suggestions in relation to usage. Both strategies can be utilised in the process of capturing meaningful outcomes.

The participation domain should relate specifically to actual functioning in everyday life as opposed to capacity to perform tasks or carry out activities. Change in actual performance in an individual's relevant environments is deemed the ultimate outcome target. The ICF coding system distinguishes "capacity" from actual "performance" when rating activities and participation. The ICF defines capacity as the *ability* to execute a task or action, while performance describes what an individual *actually does* in his or her current environment (World Health Organisation, 2001, p. 15). The A-FROM participation snapshot domain relates to actual involvement in relevant daily life situations.

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. As noted above, it is difficult to segregate broad life habits from activities and tasks. Rather, activities and tasks combine to create life habits. In addition, some life habits might be more extensive than others. For example, participating in religious life might involve multiple activities and tasks for one individual (e.g., attending church, obtaining altar flowers, making phone calls) while religious life for another person might be limited to saying a prayer each evening. Therefore, we chose not to separate activities and participation. Categories exploded out of the A-FROM participation domain (Figure 5) focus on what individuals are actually doing in daily life in relation to *roles and responsibilities, conversation, and relationships*. At this level an assessment tool might capture how the individual is participating in conversation (e.g., "Do you participate in conversation with other people?"). For greater detail the clinician might choose to delve deeper into the tasks, activities, or subcomponents that comprise conversation (e.g., "Do you join in conversation with groups?"; "Do you join in conversation with someone you know?"; "Do you initiate topics of conversation?"). With increasing detail we begin to access information on increasingly narrow tasks. At this level of assessment, the lines between domains can grow increasingly blurred—this is the realm of overlap among the A-FROM domains depicted in the circles in Figure 3. Thus, we might consider "ordering in a restaurant" as a task subsumed under the exploded domain of participation, while "naming pictures of food items in a therapy room" is more accurately captured within the domain of aphasia severity. While these distinctions become confusing, it is actually not important to the "big picture" goals of A-FROM. The purpose of A-FROM is to remind stakeholders to consider relevant outcomes at broader, meaningful levels. Therefore, if a clinician is measuring outcomes in terms of naming food items or writing cheques in the clinic, this fails to capture outcome at the broad domain of actual life participation. It might be appropriate to capture narrow outcomes; however, A-FROM reminds us that the big picture outcomes cannot be overlooked if we wish to demonstrate meaningful life changes.

Applications of A-FROM will be most useful if clinicians and researchers adopt a common scoring system to allow for collating and comparing outcome data across contexts. Since many agencies, institutions, and organisations have adopted the ICF as a guide (American Speech-Language-Hearing Association, 2001), it would be

strategic to adopt a scoring system compatible with the ICF rating system either by directly incorporating the ICF 0–4 scale or by “translating” measurements into a 0–4 scale. Although the ICF 0–4 rating system has drawbacks, it does have the advantage of being attached to an internationally accepted classification and could provide a common system for comparing data.

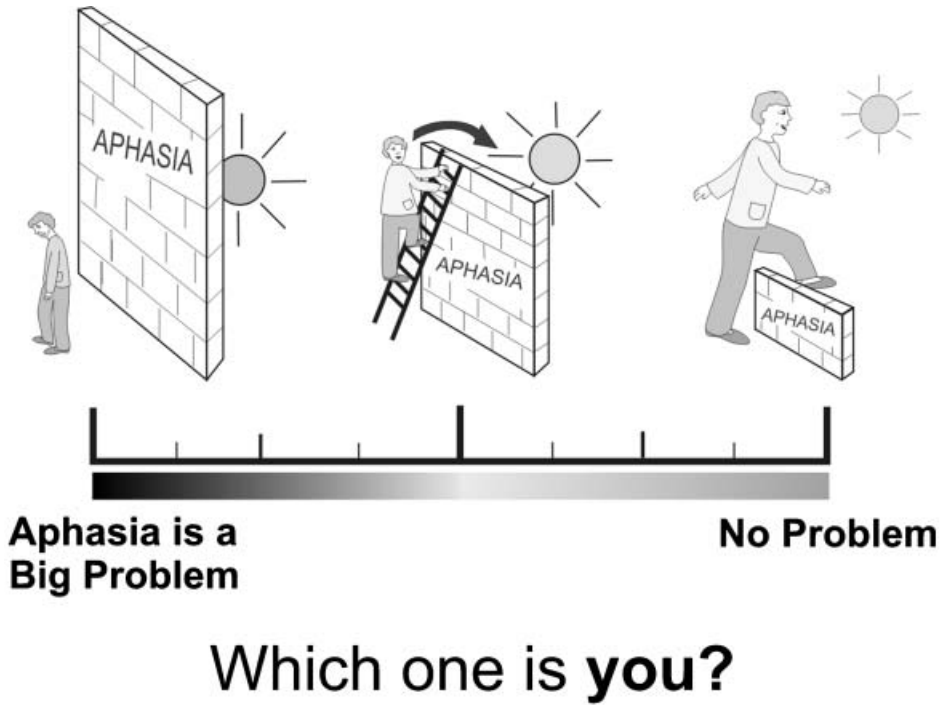
A-FROM encourages multidirectional thinking and questions. In many instances, our training encourages us to think in a linear manner, beginning with work on the impairment and then progressing through work on functional communication. A-FROM encourages non-linear thinking and questioning. For example, does a particular impairment-based treatment result in outcomes related to personal identity or increased participation? Does a social model intervention, such as a conversation group, have an impact on the severity of aphasia as measured on a traditional test?

Potential uses for A-FROM

A broad common framework for outcome measurement in aphasia allows for new opportunities including, but not limited to the following.

A-FROM for the purpose of programme evaluation. A-FROM can be used to frame programme evaluation in an integrated manner so that data are easily organised into coherent themes that are compatible with major international trends of interest to administration and funders. A-FROM domains and categories focus attention on important but at times elusive changes engendered by participation in a particular programme or intervention. For example, the A-FROM project provided a unique opportunity for retooling programme evaluation at the Aphasia Institute in Toronto, Canada. A new outcome assessment tool is currently under development. The *Assessment for Living with Aphasia* (ALA; Kagan et al., 2007) is an aphasia-friendly, pictographic, patient-reported outcome measure that samples outcomes in each snapshot A-FROM domain within the context of a conversational interview. It is designed to capture real-life outcomes for people with aphasia following participation in the Aphasia Institute programme. The assessment tool focuses on capturing outcomes in *all* domains of A-FROM for both the person with aphasia and the family member. In addition the ALA takes A-FROM values and guidelines into account. Thus, for example, the tool employs outcomes from the perspective of the affected person. The ALA asks “snapshot” questions at the broad level of the four domains, but “explodes” the domains into more narrowly focused questions within relevant categories. The conversational assessment begins by framing the process for the person with aphasia. Using the schematic in Figure 4 we have found that it is possible to convey the gist of A-FROM and the purpose of the assessment, even when the aphasia is severe. Pictographic metaphor is used to capture complex concepts such as “living with aphasia” and evaluating the extent to which aphasia does/does not get in the way (see Figure 6). Questions are focused on what is important to the person as exemplified in Figures 7 and 8. Each question is rated on a 0–4 scale in line with ICF scoring but 0.5s are inserted in between to create a 9-point numerical scale.²

The *Assessment for Living with Aphasia* has been piloted several times to date. We have found that the tool provides important information that our prior assessments



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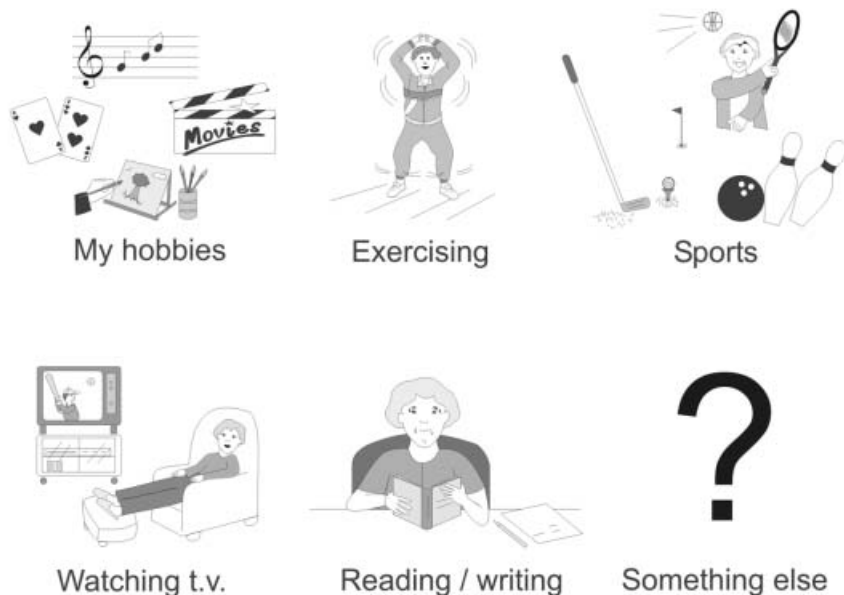
Figure 6. Living with Aphasia. From the ALA Manual, 2006, reprinted with the permission of the Aphasia Institute.

missed. We are continuing to study and refine the tool including working to explore reliability and validity.

A-FROM as a basis for establishing individual goals for individuals. Using the philosophy of “beginning at the end” (Kagan, Simmons-Mackie, & Threats, 2003), the broad domains that constitute A-FROM can form the basis for establishing individualised goals and focusing attention on opportunities for intervention that include aphasia, the environment, real-life participation, and identity and feelings. Pictographic applications such as the ALA can allow individuals with aphasia, including severe aphasia, to see the broad outcome areas where intervention can have an impact. Clients and clinicians can choose outcome targets from one or several domains. Thus, for example, therapy might include working on the attitude and skills of key conversation partners (environment), on issues related to personal identity (personal factors), on providing opportunities for genuine adult conversation (participation), in addition to efforts to improve language function (body function). A-FROM can also help clinicians to be clear about whether a particular intervention is focused on a component of “participation”. For example, work on a

² According to Streiner and Norman (2003), data from rating scales can be analysed as if they were interval without introducing severe bias provided that the distribution of scores is not severely skewed.

Leisure and Recreation



Are you **doing** as much as **you want**?

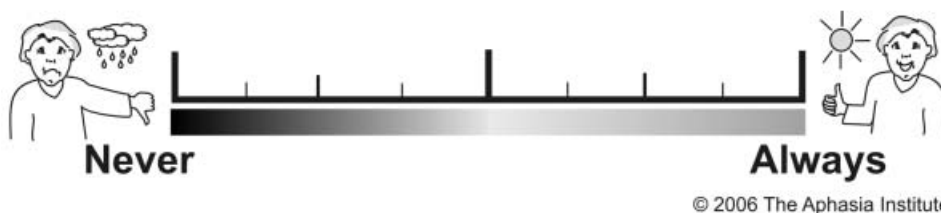


Figure 7. Doing what you want in the areas of leisure and recreation. ALA, 2006, reprinted with the permission of the Aphasia Institute.

specific functional activity or task such as practising answering the phone, asking for a cup of tea, or practising posing a WH question are not the same as *actually* engaging in conversations, facilitating interpersonal relationships, or participating in an everyday life activity such as eating out at a restaurant with friends. A-FROM was designed to help organise thinking about these multiple levels of outcome.

Including the environment as one of the major snapshots provides both a rationale and context for advocacy to increase communicative access. We know that individuals with aphasia and other communication disorders often encounter communication barriers to accessing many aspects of community and social life including healthcare.

People in Your Life



Are you happy with the number of relationships and friends?



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Figure 8. Satisfaction with number of relationships (irrespective of actual number). ALA Manual, 2006, reprinted with the permission of the Aphasia Institute.

Therefore, the environment domain provides a foundation for focusing on increasing communicative access across a range of environments.

Examining snapshot domains at points in time across the continuum of care. A-FROM is appropriate for posing broad questions at different points along the healthcare continuum. Using A-FROM to orient ourselves, we might assess outcomes across snapshot domains at specific points in time. For example, during the acute care phase of recovery the snapshot domains of A-FROM might remind us to consider assessment in the following areas: communicative accessibility of the hospital environment (environment domain), the patient's participation in decision making and goal setting (participation domain) (Simmons-Mackie et al., 2007), the

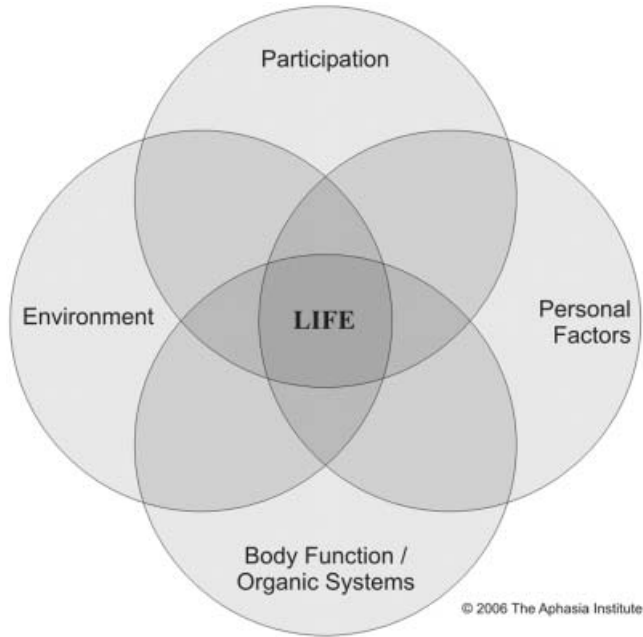


Figure 9. Framework for Outcome Measurement (FROM) Based on current classifications and models such as the World Health Organization’s ICF (World Health Organization (WHO), 2001) and the Disabilities Creation Process (Noreau, et al. 2002). Printed with permission from The Aphasia Institute.

patient’s communication (aphasia severity), and how the patient is coping with the recent onset of aphasia and illness (personal factors).

Using the “FROM” of A-FROM for different populations. With minimal changes to A-FROM, a generic version, the *Framework for Outcome Measurement (FROM)*, can be used as a guide to outcome assessment across a range of health conditions or disabilities (see Figure 9). Our teaching experience to date supports the use of this generic version as a simple and straightforward introduction to ICF and other models that focus on the complex, overlapping domains that create one’s quality of life. In the future, particular applications of FROM might result in entities such as a STROKE-FROM or a BRAIN INJURY-FROM.

CONCLUSION

Although A-FROM is compatible with other platforms (e.g., ICF) and can therefore be used in conjunction with ICF tools or translated into ICF coding, we offer the A-FROM (and FROM) as alternative guides to outcome measurement for several reasons. First, the schematics are simple and user friendly. Focus group members, colleagues, and speech-language pathology students have attested to the ease of understanding complex concepts using these schematics. The frameworks offer the advantage of simplifying the schematic and categories of ICF while retaining complexity via the “exploded” spheres. Second, they capture the dynamic interaction of life domains that are related to “real-life” outcomes. From a clinical standpoint

this reinforces the importance of considering the effects of treatment targeting one or more domains on outcome in multiple domains. This focus on the larger impact of intervention on various aspects of life is consistent with trends in health care around the world. Third, A-FROM and FROM highlight quality of life or living with a disability as a central element created by the multiple interacting domains of life. Others acknowledge quality of life (QOL) as a feature of outcome, but their models do not clearly situate QOL within their schematics. Fourth, the aphasia-specific framework, A-FROM, is specifically designed with aphasia in mind. Thus, it simplifies the defined domains and category choices considerably. ICF and DCP attend to multiple areas of health and disability (e.g., communication, mobility, self-care). While this is important from the standpoint of overall rehabilitation, it means that aphasia clinicians must negotiate an exhaustive range of categories in order to determine elements of specific interest to aphasia treatment outcomes. A-FROM accomplishes this a priori. Fifth, A-FROM is transparent and based on input from diverse stakeholder groups, capturing elements of importance to clinicians, people with aphasia and their families, as well as funders, administrators, and policy makers. Although the development of ICF incorporated input from multiple stakeholder groups, A-FROM provides input specifically from those affected by aphasia.

With slight adaptations A-FROM would be appropriate for outcomes associated with other communication disabilities (e.g., motor speech disorders) and could potentially be used to organise research. For example, it could guide the study of aphasia intervention by highlighting intervention domains where research evidence exists and pinpointing domains with little evidence to support intervention. Further development of A-FROM and development of actual tests will require subsequent work by our common community of practice. A-FROM is intended to expand on “what counts” in outcome measurement for aphasia. By integrating quality of life into the existing and widely recognised ICF model and applying concepts to aphasia, A-FROM conceptually enhances outcome measurement for people with aphasia from a person-centred perspective.

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