Stuttering and the International Classification of Functioning, Disability, and Health (ICF): An update

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Abstract

The World Health Organization (WHO) recently presented a multidimensional classification scheme for describing health status and the experience of disablement. This new framework, the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001), is a revision of WHO’s prior framework for describing the consequences of disorders, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH; WHO, 1980). In previous papers, Yaruss [J. Speech Lang. Hear. Res. 41 (1998) 249; J. Commun. Disord. 34 (2001) 163] had shown how the original ICIDH could be adapted to describe the consequences of stuttering at several levels that are relevant to the communication and life experiences of the person who stutters. The current manuscript presents an update of the Yaruss (1998) model that accounts for the new structure of the ICF. A comparison of the WHO’s ICIDH and ICF frameworks is presented, followed by an analysis of how the ICF can be adapted to describe the speaker’s experience of the stuttering disorder. Emphasis is placed on the fact that stuttering involves more than just observable behaviors. Specifically, the speaker’s experience of stuttering can involve negative affective, behavioral, and cognitive reactions (both from the speaker and the environment), as well as significant limitations in the speaker’s ability to participate in daily activities and a negative impact on the speaker’s overall quality of life.

Learning outcomes: As a result of reading this manuscript, participants will

(1) gain an understanding of the updates to the World Health Organization’s original International Classification of Impairments, Disabilities, and Handicaps that are seen in the International Classification of Functioning, Disability, and Health

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The World Health Organization (WHO) recently presented a multidimensional classification scheme for describing health status and the experience of disablement. This new framework, termed the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001), is a revision and update of the WHO’s prior framework for describing the consequences of disorders, termed the International Classification of Impairments, Disabilities, and Handicaps (ICIDH; WHO, 1980). The original ICIDH was designed to describe the consequences of diseases and disorders in terms of impairment (“loss or abnormality of psychological, physiological, or anatomical structure or function”), disability (“restriction or lack . . . of ability to perform an activity in the manner or within the range considered normal for a human being”) and handicap (“a disadvantage for a given individual . . . that limits or prevents the fulfillment of a role that is normal . . . for that individual” (WHO, 1980, pp. 25–29). One key goal of the ICIDH was to provide a common language for discussing multiple aspects of disability (Duckworth, 1984), and since its introduction in 1980, the ICIDH has been widely used throughout the health-related professions as a way of categorizing an individual’s experience of various diseases or disorders.

In a prior paper, Yaruss (1998) presented an adaptation of the ICIDH designed to describe the stuttering disorder. The goal of Yaruss’s (1998) model was to describe the experience of stuttering from the perspective of the person who stutters, taking into account the production of speech disfluencies and the potential negative consequences these disfluencies might have for the speaker’s life in general. The ICIDH was selected as the starting framework for Yaruss’s model of stuttering specifically because it examined the consequences of disorders at multiple levels of the individual’s experience, rather than focusing only on the etiology of the disorder or on the observable behaviors that characterize the disorder (see Frattali, 1998a, 1998b). Thus, in addition to using the ICIDH to describe the speech patterns of a person who stutters (impairment), Yaruss used the framework to describe the difficulties the person might have communicating in daily situations (disability), as well as the impact these communication difficulties might have on the person’s abilities to achieve his or her goals in life (handicap).

Information about these real-world consequences of stuttering is helpful not only for understanding the broad nature of the stuttering disorder, but also for evaluating the outcomes of stuttering treatments that may attempt to modify or ameliorate the negative consequences of the disorder (Yaruss, 2001). For example, Yaruss and Quesal (2001) have used the model in the development of a measurement instrument for documenting stuttering treatment outcomes. This new tool, the Overall Assessment of the Speaker’s
Experience of Stuttering (OASES), describes stuttering in terms of: (a) the observable characteristics of the speech difficulty (impairment), (b) the functional communication difficulties experienced in the speaker’s everyday life (disability), and (c) the impact of the stuttering disorder on the speaker’s overall quality of life (handicap). By examining the consequences of stuttering at multiple levels in this way, the instrument can provide a comprehensive evaluation of the benefits of intervention for individuals who have been treated using a variety of different treatment approaches.

1. Limitations in the original ICIDH framework for describing stuttering

Although Yaruss’s (1998) model was based on the ICIDH, it deviated from the original ICIDH framework in two specific ways. First, stuttering differs from many of the other disorders categorized under the ICIDH in that the negative consequence of stuttering are mediated, to a large extent, by the speaker’s reactions to stuttering. These reactions, which are often discussed in terms of the speaker’s affect (feelings about stuttering, such as embarrassment or shame), behaviors (avoidance, tension, or struggle), and cognitions (negative self-evaluation or low self-esteem), can determine whether a speaker will experience difficulties with communication and how much these difficulties affect the person’s life overall (e.g., Cooper, 1997; Manning, 2001; Yaruss, 1998). For example, some individuals who stutter severely may experience few negative consequences from their stuttering if they have learned to accept their stuttering and to minimize maladaptive compensatory strategies such as avoidance, tension, or struggle behaviors. Conversely, even people who stutter mildly may experience significant negative consequences if they fear stuttering, if they avoid speaking situations, or if they try to say only those words they think they can say fluently. To account for this complex relationship between the speaker’s reactions to stuttering and the resulting negative consequences for the speaker’s life, a component was included in the Yaruss (1998) model that accounts for these personal reactions, even though this was not explicitly addressed by the WHO in the original ICIDH framework. (As a result, the OASES measurement instrument referred to above includes components for evaluating the speaker’s affective, behavioral, and cognitive reactions to stuttering in addition to assessing the consequences of stuttering in terms of observable behaviors, functional communication, and quality of life.)

Another way the Yaruss (1998) model of stuttering differed from the original ICIDH framework is in the inclusion of the environment as a factor that could influence the speaker’s experience of negative consequences from stuttering. Even if a speaker exhibits few negative affective, behavioral, or cognitive reactions to stuttering, he or she may still experience disadvantages relative to others, or reductions in quality of life, if people in the speaker’s environment discriminate against people who stutter, tease the speaker about his or her speech, or harbor misconceptions about stuttering. Thus, when considering the speaker’s experience of stuttering and the impact of stuttering on the speaker’s life for the development of the Yaruss (1998) model, it was important to also take into account the potential role of the environment, even though this was not included in the original ICIDH.
2. A new framework: the International Classification of Functioning, Disability, and Health (ICF)

In adapting the ICIDH to the study of stuttering, Yaruss (1998) had identified aspects of the stuttering disorder that were not adequately represented within the original ICIDH framework. Similarly, numerous other authors from across the broad fields of health, disability studies, and rehabilitation, had identified concerns with the original ICIDH framework that limited its ability to describe the experiences of individuals with a variety of health concerns (Badley, 1987; Halbertsma et al., 2000; Schuntermann, 1996; Thuriaux, 1995).

Much of the initial dissatisfaction with the ICIDH had focused on the use of the terms “disability” and “handicap” (e.g., Brandsma, Lakerveld-Heyl, Van Ravensberg, & Heerkens, 1995; Heerkens, Brandsma, Lakerveld-Heyl, & van Ravensberg, 1994; Söder, 1987). These terms were widely viewed to be inappropriate labels for individuals who may have experienced health concerns, but who were not limited in their ability to participate in their lives, due perhaps to their own adaptations or to accommodations within their environment. A second concern was the fact that the role of the environment—either for hindering individuals or for helping them overcome limitations associated with their health problems—was not explicitly addressed in the original ICIDH (Badley, 1995). A third major concern was the fact that the original ICIDH did not account for various personal factors, such as coping skills and attitude, that might influence an individual’s experience of disability (WHO, 1993). This is particularly important when considering the stuttering disorder, for as noted above, the individual’s reactions to stuttering play a key role in determining the degree of disability the speaker will experience. Finally, many authors criticized the ICIDH because it focused only on the activities a person could not perform, and did not address the classification of positive experiences or activities a person could perform (Simeonsson, Lollar, Hollowell, & Adams, 2000).

As a result of these and other concerns, the WHO undertook the preparation of a major revision to the ICIDH. The process associated with the revision involved not only the evaluation of the many scholarly papers that had been written about the ICIDH; it also took into account the input from a variety of interest groups, such as researchers and clinicians from the fields of health care and rehabilitation (including speech-language pathologists and stuttering specialists), people concerned with human rights and rights for individuals with disabilities, government officials, and others. The resulting framework, now called The International Classification of Functioning, Disability, and Health (WHO, 2001), was ratified on May 22, 2001. It was rapidly adopted by many organizations, including the Centers for Disease Control and Prevention and the American Speech-Language-Hearing Association, as the framework that will be used for describing disabilities and evaluating clinical services provided to individuals with disabilities (Threats, 2001).

3. Differences between the ICF and the ICIDH

The new ICF framework preserves many of the basic characteristics of the original ICIDH. For example, it retains the goal of providing “a unified and standard language and
framework” (WHO, 2001, p. 3) for discussing health-related experiences, and it still describes health experiences at multiple levels representing a person’s abilities and experiences. The classification also continues the original goal of describing the relationship between various aspects of a person’s health experiences (e.g., the relationships between an individual’s health concerns and the difficulties he or she might experience in performing certain activities). Finally, like the ICIDH, the ICF refrains from addressing the etiology of health problems. Both the original ICIDH and the new ICF are presented as complementary to the WHO’s etiological classification system, the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10; WHO, 1992). Thus, “ICD-10 provides a ‘diagnosis’ of diseases, disorders, or other health conditions, and this information is enriched by the additional information given by ICF on functioning” (WHO, 2001, p. 4). (For this reason, the original Yaruss, 1998 model depicted etiology as separate from the components of impairment, disability, and handicap that were being described for the speaker’s experience of stuttering. For further discussion about the relationship between etiology and the ICIDH for stuttering, see Prins, 1999 and Yaruss, 1999).

Although several aspects of the new ICF remain consistent with the original ICIDH, there are many important differences, affecting nearly every aspect of the classification system. Specifically, there are changes in the purpose of the framework, the structure of the classification scheme, the terminology used to describe health experiences, and the graphical images used to represent the structure of the framework.

3.1. Changes in purpose

Most notably, the ICF seeks to classify all of the “components of health” (WHO, 2001, p. 4). This is a significant departure from the goals of ICIDH, which was designed to describe the “consequences of diseases” (WHO, 1980, p. 10). This means that the ICF addresses both the negative impact of health conditions, as well as the positive aspects of health. Indeed, the WHO does not intend the ICF to be used solely for the purpose of describing people with disabilities. The goal is to describe the health and health-related experiences of all people.

3.2. Changes in structure

In addition to fundamental changes in the purpose of the framework, there were many substantive changes to the structure of the classification. Rather than listing the consequences of disease in terms of the ICIDH’s three “planes of experience” (WHO, 1980, p. 25), the ICF describes the components of health in two parts: (a) functioning and disability and (b) contextual factors. Each of these sections is further separated into two components describing different aspects of health and health-related experiences, as follows:

3.2.1. Functioning and disability

Part 1 of the ICF provides a comprehensive summary of the experiences individuals might have with regard to their health. It is separated into two components, body functions
and structures, which replaces the list of impairments found in the ICIDH, and activities and participation, which combines and replaces the original ICIDH lists of disabilities and handicaps.

The first component, body functions and structures, covers all of the major physiological and psychological functions of an individual (e.g., mental functions, sensory functions and pain, voice and speech functions, etc.), as well as the anatomical structures that serve these functions (e.g., structures of the nervous system; eye, ear, and related structures; structures involved in voice and speech, etc.). Each list (body function and body structure) is divided into eight chapters, organized in a generally parallel fashion so Chapter 1 in the body functions list (mental functions) corresponds roughly to Chapter 1 in the body structures list (nervous system). Each chapter contains a series of three- and four-digit codes describing body functions ("b" codes) and structures ("s" codes). Impairments, or "the expression of a health condition" (WHO, 2001, p. 13), are then described for either body function or body structure using qualifying codes added to the "b" or "s" codes. Qualifiers are used to represent the nature of the structural change (with different standardized codes used to describe the change) and the degree of impairment, ranging from "no problem" (xxx.0) to "complete problem" (xxx.4).

The second component, activities and participation, covers "the full range of life areas (from basic learning or watching to composite areas such as interpersonal interactions or employment)" (WHO, 2001, p. 14). Unlike the ICIDH, which separated these life experiences into the separate areas of disability (difficulty completing daily activities) and participation (disadvantages experienced in fulfilling expected roles in personal life and in society), the ICF combines these personal and social perspectives into a single list covering nine basic aspects of life (e.g., learning and applying knowledge, general tasks and demands, communication, mobility, etc.)

Each of the items within these domains can be qualified in terms of a person’s performance and capacity. Performance is defined as "what an individual does in his or her current environment" (WHO, 2001, p. 15). Capacity, meanwhile, is defined as the "individual’s ability to execute a task or an action" or "the highest probable level of functioning that a person may reach" (WHO, 2001, p. 15). Thus, this section of the ICF provides the ability to differentiate between what a person can do in an ideal or standardized environment (capacity) and what a person actually does in his or her current environment (performance). Resulting difficulties with activities and participation are then discussed as limitations in activity or restrictions in participation, rather than as disabilities or handicaps.

It is worth noting that the final version of the ICF does not preserve any one-to-one correspondence between the old concepts of disability and handicap and the new concepts of activity limitation and participation. This correspondence was seen in the early drafts of the ICF; however, it was abandoned as a result of field testing which highlighted confusion about the distinction between disability and handicap. (It was found that practitioners did not reliably differentiate between activity and participation as defined in draft versions of the ICF, so in the final version, the two dimensions were combined into a single complex component.) Thus, in the final version of the ICF, activity limitations were defined as “difficulties an individual may have in executing activities” and participation restrictions were defined as “problems an individual may experience in involvement in
life situations’’ (WHO, 2001, p. 14), and either description may apply to an individual’s life experience depending upon the area being discussed. Finally, the ICF also allows the classification of both negative and positive impacts on activities and participation, due perhaps to contextual factors, such as accommodations in the environment or assistive devices, that help an individual to improve performance. In this way, the ICF seeks to classify all aspects of an individual’s health experience, not just negative aspects associated with disablement.

Together, the two components of the first part of the ICF describe all of the positive and negative aspects of an individual’s experience of health and daily living at a variety of levels and across a variety of domains. What this first part does not describe, however, is the various internal and external factors that may serve to influence the individual’s body structure and functions or activities and participation. These factors, which were almost entirely absent from the original ICIDH (Badley, 1995), are now covered by the second part of the ICF.

3.2.2. Contextual factors

Part 2 of the ICF describes a wide variety of contextual factors that may influence functioning and disability. There are two components in this part, describing (a) environmental factors and (b) personal factors.

Environmental factors are defined as the “external influences on functioning and disability” (WHO, 2001, p. 11), including “the physical, social, and attitudinal environment in which people live and conduct their lives” (WHO, 2001, p. 16). The ICF contains a detailed list of environmental factors focusing on two levels: individual (including the person’s immediate environment, such as work, home, or school) and societal (including social structures, cultural attitudes, etc.). The list itself is organized into five chapters: (a) products and technology, (b) natural environment and human-made changes to the environment, (c) support and relationships, (d) attitudes, and (e) services, systems, and policies. It is worth noting that the goal of the classification system for environmental factors is to identify specific aspects of a person’s experience that may affect their health experience. Thus, global descriptors such as socioeconomic status (SES) and “rural or urban setting” (WHO, 2001, p. 171) are not preferred. Rather, the coder is encouraged to separate out constituent factors that affect the person’s experience, in terms of the chapters listed above, and explicitly code the impact of those constituents individually. Finally, it is important to recognize that the influence of any of these environmental factors can be either positive or negative and, therefore, can either facilitate or hinder performance. The extent of influence is indicated by a qualifier following the classification code (0–4), with a plus sign indicating facilitation and a period used to indicate hindrance or negative effects.

Personal factors are defined as the “internal influences on functioning and disability” (WHO, 2001, p. 11), including the “particular background of an individual’s life” and factors such as “coping styles . . . past and current experiences . . . overall behavior pattern and character style, individual psychological assets and other characteristics” (WHO, 2001, p. 17). Unlike the section on environmental factors, which contains a detailed list of environmental factors that may affect functioning or disability, there is no specific list of personal factors to be considered “because of the large social and cultural variance associated with them” (WHO, 2001, p. 8). Still, as with the environmental factors, these
personal factors can have either a positive or negative effect on an individual’s health-related experiences.

3.3. Changes in graphical representation

In addition to a new structure, the ICF contains a new graphical representation designed to illustrate the interactions between the various components of body function and structure, activities and participation, and contextual factors. The original ICIDH included a rather simplistic representation showing relationships between the underlying disease or disorder and the resulting impairment, possible disability, and ultimate handicap. Although the relationships seem almost linear, the text accompanying the depiction stated that “the situation is far more complex [because] handicap may result from impairment without the mediation of a state of disability” (WHO, 1980, p. 30). Still, other than the “shortcut” relating impairment directly to handicap, the original graphical representation was relatively straightforward.

In the ICF, the interactions between components are far more complex. As a result, the new diagram offered by the WHO depicts an interactive relationship between the health condition itself (i.e., the disorder or disease) at the top level; the body functions/structures, activities, and participation at the middle level; and the environmental and personal context at the bottom level. Arrows are used to demonstrate bidirectional relationships among and between each of the three levels. Nevertheless, the text accompanying the new figure also states that:

... any diagram is likely to be incomplete and prone to misrepresentation because of the complexity of interactions in a multidimensional model. The model is drawn to illustrate multiple interactions. Other depictions indicating other important foci in the process are certainly possible. Interpretations of interactions between different components and constructs may also vary ... (WHO, 2001, p. 18)

Thus, the figure demonstrates that the ICF is designed to describe health and health-related experiences at multiple interacting levels, with sufficient flexibility to allow for different expressions of the ICF framework depending upon the characteristics of specific disorder areas. Interestingly, the WHO’s figure does not depict the fact that activity and participation are now shown in a single list (WHO, 2001, p. 14). As a result, it is likely that different graphical representations will need to be developed to reflect the specific relationships that are important for different health conditions.

3.4. Changes in terminology

Finally, accompanying these modifications to the classification scheme is the long-awaited change in the terminology used to describe health conditions. In the ICF, the term disability (or disablement) is now used in a broader sense to describe impairments, activity limitations, and participation restrictions, while the term handicap does not appear at all. Together with the modifications to the purpose and structure of the classifications, these changes in terminology shift the focus of the framework away from health problems. Now, the classification describes health experiences, both positive and negative.
4. The ICF and stuttering

Given that the ICF is likely to become the standard used by organizations such as the American Speech-Language-Hearing Association for describing health and health-related experiences, it is appropriate to consider how the new framework affects the description of the stuttering disorder. In the original ICIDH, stuttering appeared directly in the list of impairments, and it was possible to identify many aspects of disability and handicap that could result from the stuttering impairment (mediated by the individual’s reactions to the impairment as described above; see Yaruss, 1998). Because the ICF focuses on both functioning and disability, rather than just on the disability component, it is now possible to describe both fluency and stuttering, as well as other positive and negative aspects of the speaker’s experiences of fluent and disfluent speech, as follows:

4.1. Body function and structure

4.1.1. Body function

Included in the ICF’s comprehensive list of body functions is the list of “voice and speech functions” (Chapter 3). This chapter includes a section for describing “fluency and rhythm of speech functions” (Section b330), such as “functions of fluency, rhythm, speed and melody of speech; prosody and intonation.” Impairments listed under b330 include “stuttering, stammering, cluttering, bradylalia and tachylalia” but exclude “mental functions of language (b167); voice functions (b310); articulation functions (b320),” which are classified separately (WHO, 2001, p. 72).

Section b330 is then further divided into subsections describing “fluency of speech” (b3300), “rhythm of speech” (b3301), “speed of speech” (b3302), and “melody of speech” (b3303), as well as two miscellaneous subsections to allow for further elaboration of the “fluency and rhythm of speech” category, namely “other specified” (b3308) and “unspecified” (b3309). Each of these subsections contains a more detailed description of the listed aspects of speech fluency. For example, the section for “fluency of speech” (b3300) states that it refers to “functions of the production of smooth, uninterrupted flow of speech” (WHO, 2001, p. 72). Specific impairments associated with this body function are listed as “stuttering, stammering, cluttering, dysfluency, repetition of sounds, words or parts of words and irregular breaks in speech” (WHO, 2001, p. 72). Thus, a person who exhibits stuttering behaviors would be classified as exhibiting an impairment of body function under section b3300, “fluency of speech,” and a qualifying code could be used to denote the degree of the impairment. For example, b3300.1 would be the code for a “mild” problem, while b3300.3 would be the code for a “severe” problem. No specific information is provided in the ICF for how to judge severity, though percentages are offered to indicate the amount of impairment.

If the speaker experiences other impairments, including impairments in mental function (Chapter 1 of the classification of body functions), these would be classified separately. Examples include extreme anxiety or other emotional concerns (b152), which might not be diagnosed by a speech-language pathologist. Note that these impairments in mental function would be different from personal factors that might influence the
speaker’s experience of the stuttering disorder. Such reactions would best be described in the next section on contextual factors. Finally, a person who exhibits psychogenic stuttering would also be likely to exhibit either global or specific impairments in mental function.

4.1.2. Body structure

The list of “structures involved in voice and speech” is contained in Chapter 3 of the “body structure” listing. Specifically, the chapter includes sections describing the structures of the nose (s310), mouth (s320), pharynx (s330), and larynx (s340). Because there is no clearly identified structural deficit in these structures associated with developmental stuttering, these codes would not be used for classifying stuttering. Nevertheless, recent findings point to a possible structural difference in the nervous system of adults who stutter (Foundas, Bollich, Corey, Hurley, & Heilman, 2001; Sommer, Koch, Paulus, Weiller, & Büchel, 2002). These structural deficits are covered in Chapter 1 of the body structure classification (“structures of the nervous system”), and it is possible that such findings may ultimately lead to a classification for stuttering in this section of the ICF. Of course, individuals with neurogenic stuttering might also exhibit impairments in the structure of the brain or nervous system (Section s110), and these, too, could be classified using the ICF.

4.2. Activities and participation

Unlike the description of body function and structure, which includes a relatively restricted number of components that are generally affected in a person who stutters, the classification for activities and participation includes a broader range of components that might be affected, directly or indirectly, by stuttering. Thus, the most apparent component of activities and participation that can be affected by stuttering is communication (Chapter 3 of the Activities and Participation list), and, specifically, speaking (d330) or “producing words, phrases, and longer passages in spoken messages ...” (WHO, 2001, p. 134). Coding that is particularly relevant to fluency disorders is further specified in sections d350–369, which include: “starting a conversation” (d3500), “sustaining a conversation” (d3501), “conversing with one person” (d3503), and “conversing with many people” (d3504), as well as engaging in a “discussion with one person” (d3550), and a “discussion with many people” (d3551). (Note: in the ICF, conversation is defined as an “interchange of thoughts and ideas” [p. 135], while discussion is defined as “examination of a matter, with arguments for or against” [p. 136]) In addition, this section includes codes for “using telecommunication devices ... including telephones” (d3600). All of these sections describe aspects of communication that can be affected by stuttering, and it is noteworthy that the new ICF takes into account many factors that are commonly considered in the treatment of people who stutter.

Because communication is such an integral part of so many aspects of life, there are many other examples of activity and participation that can be affected by stuttering. Several examples can be found in the chapters on “domestic life” (Chapter 6), “interpersonal interactions and relationships” (Chapter 7), “major life areas” such as education and employment (Chapter 8), and “community, social, and civil life” (Chapter 9).
For example, a person who stutters might experience limitations in aspects of their domestic life if they experience difficulty in assisting others (such as their children) with communication (d6602) or in interpersonal relationships (d6603). In extreme cases, people who stutter might experience limitations in their ability to acquire goods and services needed for living (d620) due to the difficulties experienced when interacting with others in occupational or social settings. In the domain of interpersonal interactions and relationships, a person who stutters might experience restrictions in the ability to form relationships (d7200) or interact according to social rules (d7203). Stuttering may also lead to difficulties in relating with strangers (d730) in a variety of settings.

There are a number of common limitations associated with the major life areas such as education and employment that may be experienced by people who stutter. Examples include difficulties in education, which are classified in the ICF according to educational levels such as preschool (d815), school (d820), vocational training (d825), and higher education (d830), as well as informal education from family members (d810). In the area of work and employment, a person who stutters might experience limitations associated with employment (d845), such as seeking (d8450) or maintaining (d8451) work, or in the ability to earn money through employment (d850). Finally, with respect to community, social, and civic life, a person who stutters might experience limitations in a variety of domains, such as reduced participation in formal (d9101) and informal (d9100) associations like church groups or social clubs, reduced ability to pursue hobbies (d9204) or other forms of recreation in general (d920), and limitations in the ability to participate in specific religious activities (d9300).

In the new ICF framework, the activity limitations and participation restrictions that are identified for an individual are supposed to be qualified with codes representing the distinction between what the person can do in a uniform or standardized environment (capacity) and what the person does in the current environment (performance). Because different individuals who stutter react to situations differently, however, it may be impossible to identify a standard environment for assessing the capacity for fluency, particularly given the fact that the standard environment is supposed to “be the same for all persons in all countries” (WHO, 2001, p. 15). Many people who stutter are able to achieve fluent speech and positive communication attitudes in at least one communication environment, though the specific situation that yields optimal fluency is likely to differ from person to person. Furthermore, many people who stutter experience significant variability in their fluency and reactions to stuttering in other environments and over time. Thus, it may be more fruitful to examine a person’s ability to perform daily activities and participate in life across a variety of common environments and social contexts using only the qualifying code for performance, rather than trying to assess fluency in some sort of artificial standard environment.

Finally, as noted above, not all individuals who stutter will experience these limitations in activities or restrictions in participation. The degree to which speakers experience limitations in activity or restrictions in participation in any of these areas will be strongly influenced not only by the severity of the stuttering impairment as described above, but also by their personal reactions and other contextual factors such as the reactions of those in the speaker’s environment.
4.3. Environmental factors

A variety of environmental factors can influence the experiences of a person who stutters. For example, Chapter 1, “Products and Technology,” describes devices and equipment for personal use in daily living (e115) or, specifically, for communication (e125), that might affect the fluency of individuals who stutter (e.g., an electronic device that may be used to facilitate fluency). Other examples of the way in which the environment can influence a speaker’s experience of the stuttering disorder can be found in Chapter 3, “Support and Relationships.” This section lists various individuals from whom a speaker might receive either facilitation and support or restriction and hindrance, such as the immediate (e310) or extended (e315) family, friends (e320) and acquaintances (e325), etc. One example of a positive environmental effect is the student whose teacher (e360, “other professionals”) provides encouragement to increase a child’s willingness to participate in oral reading exercises. An example of a negative environmental effect is a person who is not given an opportunity to make presentations at work or gain career advancement because of discrimination against stuttering by his boss (e330, “people in positions of authority”). A more complicated example would be a person who asks his spouse (e310, “immediate family”) to make phone calls for him rather than using the phone himself. In this case, the environment would be facilitating the person’s ability to participate in activities he might otherwise miss, even though the overall impact of this facilitation may be a hindrance in the speaker’s ability to face stuttering and learn to live with it.

While Chapter 3 of the ICF describes the support that is provided by people in the speaker’s environment, Chapter 4 relates more to the attitudes of those people, as well as the attitudes that prevail in the society in which the speaker lives. More specifically, attitudes are defined as the “observable consequences of customs, practices, ideologies, values, norms, factual beliefs, and religious beliefs” that “influence individual behavior and social life at all levels” (p. 190). The classification is organized in terms of the particular persons or segments of society that hold the attitudes. Thus, if a person experiences ridicule or discrimination because of inaccurate stereotypes about stuttering, this could be classified as a negative influence of societal attitudes (e460). Similar classifications can be made regarding the attitudes of immediate (e410) or extended (e415) family, friends (e420), and others.

The last chapter of the classification of environmental influence refers to “services, systems, and policies” that might affect the speaker’s experience of stuttering. One common example includes “communication services” (e530), such as the telephone, which can hinder the ability of a person who stutters to communicate because many people who stutter experience significant negative reactions to telephone usage. On the other hand, this section might also apply to alternative communication systems such as electronic mail that might facilitate a person’s ability to participate in activities that might otherwise be difficult to access due to the person’s difficulty speaking or their feelings about stuttering. (An example would be the support that many people who stutter receive through online discussions with other people who stutter, as is seen on the STUTT-L discussion list; Starkweather, 1995.) Finally, this chapter of the classification also refers to education and training services (e585), such as school-based speech therapy services, which can serve to minimize the effect of the stuttering disorder. Notably, this chapter also includes “associations and organizational services” (e5550), including support and self-help groups, such as
the National Stuttering Association (NSA), as well as other organizations organized by people with common interests.

4.4. Personal factors

The last construct included in the ICF involves personal factors that influence a person’s experience of health. As noted above, no specific list was developed because of the vast differences in personal experience across individuals and across cultures. Instead, personal factors were simply defined broadly to include “gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experiences (past life events and concurrent events), overall behavior pattern and character styles, individual psychological assets and other characteristics” (WHO, 2001, p. 17). It was left to the individual using the classification system to identify which of these or other personal issues might play a role for the specific disorder area under consideration.

Because this aspect of the classification system was left unspecified, it will probably be difficult to develop an agreed-upon set of personal factors that influence stuttering. (This is true for many disorders, and is probably the main reason that no list was created.) It is clear that many of these personal factors can affect the speaker’s experience of stuttering in a variety of ways. Nevertheless, it is not clear how the contribution of age, gender, social background, etc., might be represented in a model for describing the experience of stuttering across speakers.

To address this concern, a consistent set of personal factors that could apply across individuals was sought. Throughout the stuttering literature, numerous authors have highlighted the important role of the speaker’s reactions to stuttering. As noted above, these personal factors are often described in terms of affective, behavioral, and cognitive (ABC) reactions (e.g., Cooper, 1997; Manning, 2001; Yaruss, 1998). Because of the important role the speaker’s reactions can play in determining whether people will experience negative impact in their lives because of their stuttering, it seemed reasonable to continue the use of the ABC framework in further considerations of stuttering and the ICF. Specific examples of personal reactions that might influence stuttering include the feelings a person might have about their speech. Although many of these feelings are regarded as negative (e.g., embarrassment, fear, anxiety, shame), there are also some positive feelings that can be identified as a person learns to cope with stuttering (e.g., hope, acceptance, optimism). Examples of behavioral reactions can include physical tension and struggle behaviors used in an attempt to prevent stuttering, as well as avoidance of words or speaking situations. Finally, examples of cognitive reactions include negative self-evaluation and reduced self-esteem on the one hand, and confidence in speaking ability on the other. All of these different reactions can influence not only the speaker’s fluency in a given situation, but also the overall experience of the stuttering disorder.

5. Updating the Yaruss (1998) framework

Fig. 1 contains an updated version of the Yaruss (1998) framework that reflects the new structure of the ICF and takes into account the key differences between the ICF and the
Fig. 1. Graphical representation of how the World Health Organization’s *International Classification of Functioning, Disability, and Health* (ICF) can be applied to the stuttering disorder.
ICIDH. As noted above, however, the model of stuttering had already deviated from the original ICIDH in that it included components representing personal factors (affective, behavioral, and cognitive reactions to stuttering) and environmental factors that may affect an individual’s experience of the stuttering disorder. With the ICF, these components are explicitly included in the model, and because the experience of stuttering is significantly affected by the reactions of the speaker and those in the speaker’s environment, they remain in a central position.

Perhaps the most noteworthy difference between the ICIDH and the ICF is the fact that the list of activities and participations is combined in the ICF, and there is no longer any distinction between “disability” (i.e., difficulty performing tasks) and “handicap” (i.e., disadvantages experienced in the ability to achieve life goals). The model shown in Fig. 1 reflects the new relationship between activity and participation by combining these two factors into a single component with two interrelated aspects.

The model, therefore, demonstrates how a person who stutters (i.e., a person who experiences an impairment in body function affecting fluency of speech [b330]) can also experience affective, behavioral, and cognitive reactions (personal factors) that can limit his or her ability to participate in certain activities associated with speaking (d330), holding conversations (d350), or other aspects of social interaction as indicated in the figure. The individual may experience these same limitations in his or her ability to participate if there are aspects of the environment that hinder communication (e.g., negative or stereotyped attitudes of society or individuals [e400]). Either way, these limitations can affect both the speaker’s reactions to stuttering and the reactions of those in the speaker’s environment. The model also indicates how the reactions speakers receive from other people can influence their own reactions to their stuttering. The reverse is also true—speakers’ reactions to their stuttering can influence how other people in their environment respond to them. Finally, the model shows that reactions to stuttering (both those of the speaker and those of the people in the speaker’s environment) can affect the impairment in body function (i.e., the stuttering itself). (Note: many people who stutter report that they stutter more when they are trying to be more fluent [personal factors] or when they face a conversational partner who holds stereotyped views about stuttering [environmental factors]). This revised framework can be used to broaden the understanding of stuttering, to place stuttering in the context of other health-related conditions in other fields, and to support the development of instruments for assessing treatment outcomes at a variety of levels with direct relevance to the life of the person who stutters.

6. Conclusion

The ICF provides a common language for describing the experiences of people who stutter, as well as those experiencing a variety of other conditions, in terms of the impairment in body structure or function and the resulting limitations in the individual’s ability to perform daily activities or participate in life. The model represents an advance over the earlier ICIDH framework because it specifically incorporates contextual factors (environmental and personal) and demonstrates the impact these factors can have on a person’s overall experience of health.
The ICF is particularly relevant to stuttering because it focuses on more than just the observable characteristics of disorders. For stuttering, the ICF supplements information on observable characteristics (such as repetitions, prolongations, and hesitations that may characterize stuttering) with information about the overall impact of disorder (including negative communication attitudes, shame, embarrassment, and limitations in an individual’s ability to participate in society). In addition, the ICF allows the description of both hindering factors (such as negative responses to a person’s stuttering) and facilitating factors (such as speech therapy, support groups, and an accepting environment).

The specific framework presented in this paper (see Fig. 1) demonstrates that many different factors can contribute to a speaker’s experience of stuttering, including the speaker’s reactions to the disorder as well as the reactions of those in the speaker’s environment. Because there are so many internal and external factors that affect the individual who stutters, it is not surprising that different speakers can have vastly different experiences with their speech and speaking difficulties. This variability (both between and within speakers) is a fundamental aspect of the stuttering disorder that speech-language pathologists need to understand, so it is particularly appropriate that the revised ICF includes components that directly address these influences. Indeed, the fact that the ICF highlights these aspects of the individual’s experiences of stuttering highlights the importance of these components for understanding the entire stuttering disorder and demonstrates that all human conditions are comprised of more than just the observable behaviors. For this reason, the ICF is a useful framework for describing the stuttering disorder, and the model proposed in this paper is a meaningful way of interpreting the experiences of people who stutter.

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Appendix A. Continuing education

1. The purpose of the *International Classification of Functioning, Disability, and Handicap (ICF)* is to:
   a. describe the diagnosis of various disorders that people might experience
   b. describe the consequences of diseases and disorders
   c. update and expand the WHO’s original *International Statistical Classification of Diseases and Related Health Problems*
   d. update and expand the WHO’s original *International Classification of Impairments, Disabilities, and Handicaps*
   e. both (b) and (e)
2. The ICF differs from the WHO’s original classification scheme in that it:
   a. eliminates the use of the term \textit{impairment}
   b. incorporates contextual factors that may affect a person’s life
   c. specifies a particular diagram that is supposed to be used for all disorders
   d. provides a detailed list of specific personal factors that cause disorders
   e. incorporates a more thorough list of etiologies

3. According to this article, the ICF is valuable for the study of stuttering because:
   a. it includes multiple factors that describe the impact of a disorder on a person’s life
   b. it places the discussion of stuttering within the context of other health conditions
   c. it provides a flexible framework that clinicians and researchers can adapt depending upon the needs of the individual
   d. it is a broad-based framework that can be used to describe the effects of a wide variety of treatment programs and approaches
   e. all of the above

4. When applying the ICF to stuttering, practitioners should be certain to:
   a. calculate the frequency of disfluencies as a direct indication of the impact of the disorder on the speaker’s life
   b. list several different impairments in body structure that are thought to cause stuttering in the majority of cases
   c. consider various environmental factors that may facilitate or hinder communication success
   d. focus only on what the speaker \textit{could} do in an ideal situation, without considering what the speaker \textit{actually} does in other situations
   e. none of the above

5. The purpose of the model presented in Fig. 1 of this paper is to:
   a. apply the ICF framework to the study of stuttering
   b. depict several different aspects of the speaker’s experience of stuttering
   c. highlight the relationship between the stuttering behaviors and the impact of stuttering on a person’s life
   d. demonstrate the central importance of the speaker’s reactions to stuttering in determining the impact stuttering will have on a person’s life
   e. all of the above

References


