

Edited by

Nan Bernstein Ratner

E. Charles Healey

STUTTERING
RESEARCH
AND
PRACTICE

Bridging the Gap

Stuttering Research and Practice: Bridging the Gap

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Stuttering Research and Practice: Bridging the Gap

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Preface

The American Speech-Language-Hearing Association's Special Interest Division for Fluency and Fluency Disorders initiated "annual Leadership Conferences" in 1994. The primary goal of these annual leadership conferences is to bring together clinicians, researchers, and self-help leadership personnel to identify and address current issues in the assessment and treatment of those experiencing a fluency disorder. The Third Annual Leadership Conference held in Monterey, California in 1996 was entitled "Research and Treatment: Bridging the Gap." In retrospect it became apparent that the papers presented at the conference reflected accurately the current and the cutting-edge thinking of leading clinicians and researchers in the profession. The Division's Steering Committee concluded that the inclusion of those papers in a single volume would make a significant addition to the literature in the field.

The Steering Committee of the Division for Fluency and Fluency Disorders is pleased to have participated in the production of this volume. Special thanks are extended to E. Charles Healey and Nan Bernstein Ratner who served not only as editors for this collection of papers but as Conference Co-Chairs for the Third Annual Leadership Conference on "Research and Treatment: Bridging the Gap."

Finally, the Steering Committee wishes to express its appreciation to the authors of these papers, to those who participated in the Third Annual Leadership Conference, and to the many other individuals who made this volume a reality.

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Division for Fluency and Fluency Disorders
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Weston, FL
March, 1998*

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1 Bridging the Gap Between Stuttering Research and Practice: An Overview

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Despite decades of research and clinical work in the area of stuttering, it is the perception of many that a gap exists between how researchers and clinicians view the disorder. Many researchers claim that clinicians employ practices with dubious roots to either efficacy or basic research in stuttering; that they are “not up on the literature.” By contrast, it is not unusual to hear clinicians claim that most published literature appears to have little direct relevance to clinical concerns in the treatment of stuttering. This gap in the appreciation of what clinicians and researchers perceive they can offer each other appears to be an ongoing problem in the field of stuttering.

In May 1996, a conference was held in Monterey, California as a first attempt to bridge the gap between researchers and clinicians. The conference was sponsored by Special Interest Division #4, Fluency and Fluency Disorders, of the American Speech-Language-Hearing Association (ASHA). The program was compiled to allow for a variety of broad perspectives on the nature and treatment of stuttering and how the gap (perceived or real) between researchers and clinicians could be narrowed. For each topic, we endeavored to pair individuals with interests in empirical research methods with scholar-practitioners. Group discussions followed the presentations and the conference ended with a plenary session. In our comments that follow, we note audience response to some of the issues raised by the contributors to this volume.

A broad representation of topics is covered in this text, including general approaches to bridging the gap between research and clinical work. This volume begins with chapters by Conture, Smith, and Yairi, who present a number of conceptual issues regarding the current status of stuttering research and therapy. De Nil and Ludlow provide us with discussions of issues relative to physiological aspects of stuttering that relate to the clinical management of stuttering. Various perspectives associated with the multitude of factors related to conducting research and treating stuttering in children and adults are provided by Guitar, Riley, Gottwald, Hill, Onslow, Siegel, Manning, and Murphy. The volume concludes with two widely diverse perspectives by Ingham and Cordes, and by Starkweather on how treatment efficacy in stuttering should be addressed.

Ed Conture got the conference off to a humorous start with an instructive tour of the rocky voyages undertaken by persons who stutter, by their clinicians, and by those who conduct research in stuttering. His metaphorical description of the voyages of the *U.S.S. Fluency* is apt: fluency research and practice often seem to have navigated the globe, not once, but on numerous occasions, discovering and highlighting anew on repeated voyages the very same themes that caught our attention many years ago. The more that the ship's technology changes, the more the route seems to gravitate toward familiar paths. The student of the field who analyzes its historical roots (Bloodstein, 1993) will note that researchers such as Ludlow and De Nil are current staff bearers for notions about the neurological and specifically, cortical, basis of stuttering first researched by the founding generation of speech-language pathologists in the early years of this century.

His four "sailing instructions" have merit but are not without controversy. For example, his first instruction was to discontinue the "grind to find" research common to our field. According to Conture, throwing out large data nets to catch a few useful research findings does not result in meaningful advancement of our understanding of stuttering. However, Guitar notes later in the volume that some of our most notable scientific advances arose somewhat serendipitously and may characterize clinical discoveries made by a clinician-scientist. But accidental insights into major problems occur in a world where stuttering research is programmatically organized and motivated, as well. An important question is what constitutes irrelevant or unmotivated research. On this question, participants differed widely in their opinions, particularly when it came to deciding the boundaries of the disorder and its relevant aspects for research and therapy. Some attendees professed more interest in discovering effective treatments, even serendipitously, than in understanding how they work. From treatment might come increased understanding of cause. For others, only better understanding of cause had the potential to improve treatment.

An equally important construct for researchers and clinical practitioners in fluency is the distinction among the terms disability, impairment and handicap. Disability has long been a focus for researchers, who in fact are often pressed to address the clinical relevance of their findings in the discussion sections of published journal articles. Conture suggests that even if we understand and can change the disability (i.e., the overt manifestation of the disorder), that this does not necessarily change the handicap of stuttering, a viewpoint supported by Manning and Starkweather (this volume). For some persons who stutter, and the professional who treats them, there is less concern about removing the underlying disability than in remedying the handicap of stuttering (i.e., the disadvantages of living with the disorder). The researcher often seems to avoid such issues, finding them too removed from objective measurement, nontheory based, and too prone to produce heterogeneity in subject performance that vitiates against clear and publishable findings.

At the end of his chapter, Conture notes that our treatment approaches need more careful evaluation, both in terms of furthering the development of more effective treatments, as well as satisfying increasing demands for accountability in therapeutic practice. His concise tutorial provides options for assessing the efficacy of clinical

intervention, designs that are functional and realistic. His closing observation is brief but important: It is less important in the short run for us to know whether one approach is better than another than for us to know whether any treatment is achieving its stated ends. For some populations, notably young children, this is a critical issue, as researchers and clinicians tangle with the thorny issue of whether therapy has truly been the agent for recovery in a population known to experience unaided remission from the disorder. Even in adults, the question of whether approaches work, or whether some work better than others, is less than trivial to answer, regardless of design or subject numbers. If one cannot clearly determine what constitutes a positive therapeutic outcome, how can therapeutic efficacy be evaluated?

It was this issue: "What constitutes a positive therapeutic outcome?" that perhaps most polarized the persons who stuttered, the researchers, and the clinicians who attended the conference. Certainly, any post therapeutic outcome that produces perfectly fluent speech that can be utilized in all environments without undue hardship on the patient, and that produces speech-related attitudes and beliefs that resemble those of normally fluent speakers would be considered efficacious. But the use of such a standard to define efficacy in all cases misses our low level of understanding of the tractability of stuttering across patients, even given rather uniform intervention protocols. The medical profession has long recognized that individual response to quite finely controlled pharmaceutical treatments can vary considerably, as well as the fact that a drug may be beneficial in reducing the symptoms of the disorder, but may produce side effects that diminish the drug's effectiveness in treating the patient's original complaint. For many clinicians and patients, this understanding appears tacit: A successful treatment program is not defined as the complete absence of symptoms, but whether the treatment has reduced the disability and handicap of stuttering.

This real-world state of affairs suggests that clinically relevant improvement might remove only portions of the "stutterer's complaint," as one presenter commented, which brings up the thorny issue of deciding what the complaint actually is. One presenter professed that the complaint is obviously the speech disruptions that characterize the observable symptoms of stuttering to listeners; if they are removed, the complaint is solved. This potentially narrow definition of handicap seemed quite palpably inadequate to some clinicians and researchers who themselves stutter. It recalled a past ASHA convention paper presentation that contrasted the therapeutic approaches taken by speech-language pathologists with and without personal histories of stuttering (McFarlane & Goldberg, 1987). Their survey of clinicians showed that fluency-shaping approaches, which tend to concentrate on the elimination of speech behaviors without emphasis on less observable handicapping speech beliefs and behaviors, were most likely to be employed by clinicians with no history of stuttering symptoms. Conversely, stuttering-modification and anxiolytic approaches were most likely to be added to fluency-shaping therapies by clinicians who themselves had experienced stuttering. As Riley notes later in the volume, such observations should tell us something about the depth of the stuttering syndrome that may be less easily appreciated by normally fluent clinicians and researchers.

Perhaps those who have never stuttered have a difficult time appreciating the complexity of the disorder and its effect on the individual. Viewing stuttering as a dynamic rather than a static disorder is the central theme of Anne Smith's chapter. Smith asks us to step back from conventional approaches to stuttering and adopt new perspectives on how best to investigate and characterize the disorder. She cleverly shows how the evolution of scientific investigations of stuttering can be made analogous to the study of volcanoes. She emphasizes that when we concentrate on the overt symptoms of stuttering (e.g., volcanic eruptions), we lose sight of the dynamic process of stuttering in much the same way that classifying volcanoes according to eruption types fails to account for the dynamics of tectonic plate movement underlying volcanic activity. Thus, we can measure the symptoms of stuttering, such as the amount of air flow or tension in the speech musculature via EMG activity, but isolating their primary source is meaningless unless it is placed within the context of a multifactorial model of stuttering. Smith, as do other contributors, emphasizes the multifactorial inputs to stuttering events and to the resulting generalized disorder of speech. She concentrates on system-internal interactions among the motoric, cognitive, linguistic, and affective components of the speech and language production system.

Smith also emphasizes the likelihood that stuttering is best described by nonlinear models. Speakers move from extremely fluent to extremely disfluent moments, seemingly at random. As Yairi notes in his chapter, stuttering rarely develops along the idealized maturational paths described in our literature. Nonlinearity poses extremely interesting problems for understanding the inputs to behavior, and has interesting implications for seeking relationships between external events (such as situation or family interaction) and stuttering. If stuttering is either somewhat quantal (as in the notion of attractor states), or is characterized by other nonlinear patterns of prediction, then contrasting the degree to which X predicts Y may be highly frustrating for clinicians and researchers alike.

Given the high degree of variability surrounding stuttering, Yairi discusses a number of epidemiological factors that have the potential to either greatly inform or cloud the results of stuttering research and studies of stuttering therapy efficacy. He argues that information we have about the genetics of stuttering and phonological disorders in children who stutter is greatly influenced by the interaction of age and gender of children studied. Yairi notes that many individuals who stutter are the products of both genetic heritage and home environments in which stuttering can be observed in family members of the person under study. Yet, few studies that examine the environmental factors that may precipitate or aggravate stuttering take note of this important fact and distinguish parents who stutter from parents who do not in family analyses of stuttering. Children receive a complex heritage from their parents: predispositions to talent (or weakness) in areas of development, as well as an affective disposition from their ancestors that may aid or hinder them in negotiating life's obstacles (Kagan, 1994; Locke, 1993).

Yairi also expresses some concern about how the issue of spontaneous recovery from stuttering in early childhood has been addressed. Although

spontaneous recovery has important ramifications for counseling parents about the necessity or wisdom of clinical intervention in early childhood, it complicates the evaluation of the efficacy of therapies for early stuttering. We are just now beginning to appreciate how spontaneous recovery is related to other factors rarely discussed in reporting either research findings or therapy outcome data, such as subject gender, family history of chronic stuttering, and concomitant disorders of communication. Knowing that such factors have predictive value for some aspects of stuttering, such as spontaneous recovery, raises the standard for reporting subject characteristics in our literature. Whether particular factors result in particular patterns of responsiveness to therapy or to differential performance on research tasks is unknown, but should bear scrutiny.

Guitar leads the theme discussion of how one closes a gap between science and practice in a discipline by examining its fundamental causes. Science and practice often attract differing personalities and abilities, differences that may or may not be easily overcome by cooperation between individuals, and that may be difficult to reconcile within a single individual. After evaluating different models for solving this perennial problem, Guitar concludes that we can make great headway in understanding stuttering and its treatment if we provide more outlets for clinicians to more easily disseminate their treatment findings, so that both their colleagues and researchers can examine them. He also argues that some students in training are better suited to be scientists than clinicians and vice versa. In pairing individuals with respective talents but a common domain of interest, the field could reap the benefits of each other's knowledge and expertise.

Following the Guitar chapter, we shift to a discussion of how the neurobiology and neuropsychology of stuttering facilitates our understanding of the disorder. First, Ludlow considers whether or not we can reliably identify persons who have a distinctive profile of stuttering speech ability and performance that discretely distinguishes them from "fluent" individuals. If stuttering is our perceptual interpretation of events (and speakers) that lie on a continuum, rather than in a unique category, most of our research undertakings will be flawed by an inability to specify who the subjects of study should be. Moreover, many medical conditions are characterized by developmental staging that meaningfully affects the symptoms and treatment of the disorder. Our research rarely stratifies populations into the multiple plausible groupings that Ludlow proposes; changing our subject designs in the ways she suggests may cast new light on our understanding of stuttering. Ludlow also notes subject concerns in specification of the genetic/familial history of stuttering (echoed by Yairi in his chapter), the delineation of other speech-language abilities, and information about physical or emotional events proximal to the first symptoms of stuttering. In her view, clumping subjects for analysis may be one of the reasons we fail to produce research with interpretable and clinically relevant findings.

De Nil takes a different approach to the complexity of stuttering. He notes that the neuropsychological and neurophysiological concomitants of stuttering may be far reaching and may interact. Specifically, he tackles the commonly reported differences between fluent speakers and stutterers for lateralization of speech-

language functions. He notes that we cannot ascertain how such lateralization differences arise, but provides new and fascinating data to show that they are modified by therapeutic experience.

Clinicians often remark on the effort required to maintain fluency for the person who stutters. De Nil translates aspects of this effort and its associated construct, attention, into new findings that suggest increased activity in the anterior cingulate for people who stutter. Heightened activity in this region may be associated with decreases in automaticity, providing neurological confirmation of clinician and patient reports. Therapy has the potential to create fluent speech that is mirrored by changes in neural activation patterns, suggesting that some neurological correlates of stuttering, whether they are causative, contributive or simply the by-product of fluency failure, are not etched in stone, but are malleable given appropriate intervention.

Ludlow and De Nil provide a neurological framework for learning more about stuttering; Riley's chapter sets the stage for a discussion of clinically grounded research. She discusses the vast heterogeneity of children seen for treatment of their stuttering. Heterogeneity is the bane of experimental design, but is a fact of life we must deal with. Riley lays out possible evaluation and treatment approaches to describing and accommodating the differences among therapy patients. A second theme of her discussion continues a question raised in other chapters: What should the goals of therapy be? From the perspective of a researcher, clinicians should use data-based procedures for establishing fluency, an argument supported by Ingham and Cordes. However, therapy that creates fluency may not solve the problem of stuttering, if the person who stutters finds using fluency techniques cumbersome or if therapy ignores features of stuttering "under the surface," as Manning suggests in his chapter. Riley strongly endorses making the patient an integral part of therapy, allowing the patient to fully describe their concerns, and encouraging the patient to evaluate the outcomes of therapy in multidimensional ways that go beyond the simple reduction of stuttered moments. Her preliminary therapy outcome questionnaires provoke us to consider how patient satisfaction can be objectively described and explained, and how patient outcome reports relate to clinical goal setting.

In her final comments, Riley, perhaps more strongly than any other contributor, notes that progress is impeded when clinicians and researchers cannot mutually respect one another's approaches to stuttering. Researchers dismiss the results of clinical reports, arguing that their designs are flawed. Too many extraneous variables are uncontrolled, statistical analysis is lacking. Clinicians bypass research reports, finding them either irrelevant (or not made relevant) to clinical practice, or too narrowly controlled to be either practicable or effective with the clients on their caseload. The two groups can continue to disregard one another, but the final casualty is the person who stutters. Riley offers examples of how collaborative work can overcome such obstacles. Her examples are echoed by others in this volume, most obviously De Nil, whose work with Kroll has linked subtle changes in cortical neural activity with a form of precision fluency shaping therapy.

Siegel's chapter focuses on the importance of how our understanding of the nature of stuttering has evolved from a long history of research and clinical practice. Through a review of the contributions made by some of the pioneers in our field (e.g., Travis, Johnson, Van Riper, and Goldiamond), Siegel reminds us that these individuals recognized the contributions and important ramifications the behavioral, affective, and cognitive components of stuttering had for basic research as well as for clinical practice. Consequently, it seems difficult to separate the contributions of one component from the others. Even when strictly behavioral approaches to stuttering appear to work, are they devoid of affective and cognitive manipulation, or are we merely masking such parameters with focused terminology? As Siegel notes, operant approaches to stuttering, such as time out (TO), are particularly fascinating to analyze within alternative frameworks. What constitutes sufficient reward or punishment to change an individual's behavior? Is one person's punishment another person's reward of sorts (such as use of TO to refocus fluency enhancing knowledge)? Moreover, why should response contingencies alter stuttering in the absence of giving the stutterer tools to accomplish this end?

Manning raises a cautionary note when evaluating the effectiveness of therapy. He suggests that different therapies focus on different aspects of the complexities of stuttering, and thus, that all can claim some modicum of success. Yet, effective therapy of any sort must teach active use of techniques, and must enable their use under conditions that are likely to require a rather mature reaction to fear of failure or distraction. Given this, is it any wonder that many of the substantial number of "recovered" or perceptually quite fluent adult stutterers among us report that success for those who did not recover early in childhood was most likely to come during their mid-20s (Hood et al., 1996)? For patients, clinicians, and researchers, understanding probable windows of opportunity, as well as probable stages of life when maximal progress in therapy is less likely to be achieved is as important as which treatment approach is followed. Some of us compare the cognitive as well as the behavioral aspects of fluency therapy to sports psychology in that the technique is nothing if you can't use it under stress. The maturity of the adult patient (and the lack of such maturity in younger patients) may provide an important component of stuttering therapy not easily captured by describing the clinician's goals and strategies, no matter how scientifically sound.

Manning makes another critical observation that directly impacts our ability to judge the therapeutic outcomes of stuttering intervention. He proposes that many cases of therapeutic success become evident only after clients have left therapy — that recovery from stuttering may have its roots during direct therapy, but flower later in the patient's life, as maturity enables control over the behavioral, cognitive, and affective components of stuttering. If this is true, and testimony from many adult stutterers make this quite likely, it becomes even more difficult to ascertain what aspects of therapy or of the therapeutic relationship are most likely to produce lasting change and why certain aspects of any treatment program are effective or not. If therapeutic success is achieved long after therapy has ended, how are we to measure therapy outcomes realistically? It is also difficult to leave Manning's chapter without acknowledging its other message to researchers and

clinicians: What we do, when we do it well, makes a difference. No dispassionate discussion of stuttering can capture the essence of therapeutic success.

Manning's chapter provides a logical segue into Murphy's discussion of two emotional scars that appear early in the development of stuttering: shame and guilt. Too often, emotionality has been highlighted (unsuccessfully) as a possible cause of stuttering behaviors. Rather than as a cause of stuttering, Murphy focuses on what stuttering, like other chronic diseases of childhood and later life, does to the emotional well-being of the individual and his or her family. In this regard, he refers us to literature in psychology, a growing literature base that shows how shame and guilt reactions can adversely affect therapeutic success if they are not recognized and addressed. Moreover, Murphy suggests that clinicians who focus too much on teaching a child to speak fluently may actually increase shame and guilt, albeit inadvertently. For some clients, what may be an unrealistic quest for stutter-free speech through a pure "fluency shaping" approach may create or reinforce deep underlying feelings of shame and guilt about stuttering. These emotions can impede a client's ability to use fluency techniques, and can create ever deepening negative emotions when fluency failure continues. Parents also can develop unrealistic expectations for fluency and, in turn, become the "stuttering police" for their disfluent child. This is consistent with Manning's belief that working only with the "surface structure" of stuttering will not produce effective changes. Shame and guilt represent at least two factors that are not dealt with in fluency shaping therapy. Murphy offers suggestions for clinicians that may positively impact these underlying emotional consequences of stuttering.

The next three chapters by Hill, Gottwald, and Onslow and Packman focus on differing approaches to the treatment of preschool-age children who stutter. First, Hill suggests that understanding an individual child's particular strengths, weaknesses, and personal history is critical to optimum treatment. For the children she sees, no single approach to providing fluency skills appears to work unless it is tailored to the child's ability to use language and to coordinate speech gestures, as two examples. Her case studies illustrate how therapy can be customized to the individual needs of children and families.

Hill also tackles some widely held beliefs about the onset of stuttering. Her clinical research protocol has employed standardized assessment of the stressors that children experience near the onset of stuttering. Using such assessment protocols rather than anecdotal reports, she is unable to link the onset of stuttering to unusual trauma or stress in childhood, thus providing some of the first data to evaluate the claim, often made by parents and clinicians, that stuttering is precipitated by high levels of stress in the child's environment. Although preliminary, her data suggest that further inquiry into this topic has the potential to be quite informative for both clinicians and the families of children who stutter.

Gottwald examines the family dynamics of children who stutter. In particular, she is concerned with evaluating the efficacy of instructions given to parents to ameliorate stuttering symptoms. Among these are speech rate changes, alterations in conversational tempo (turn taking), and changes in linguistic demand. As she notes, there are little data to suggest that parental behaviors precipitate stuttering

in children, and the few differences that have been noted between parent–child interactions involving stuttering and nonstuttering children are quite likely to be the result, rather than the cause, of fluency disorder in these children. Gottwald calls for increased research into the efficacy of environmental manipulations to facilitate fluency and the use of other populations of communicatively impaired children as comparisons to parent–child interactions in stuttering. She also proposes that there is a need for the differential evaluation of children’s and parents’ profiles in the prediction of who may benefit most (and least) from such forms of “indirect” therapy for stuttering.

Onslow and Packman report a very different approach to the treatment of stuttering in children. Using behavior modification procedures, they find that stuttering can be greatly reduced by praising children’s fluent attempts and acknowledging and correcting stuttered moments. While the approach is couched within a model of response-contingent reinforcement of speech events, readers may detect features from other approaches to fluency enhancement, such as an emphasis on praising the child when he is successful, acknowledging the child’s difficulties rather than ignoring them, and guiding the child through successful motor practice of difficult words. The program has produced impressive results that do not appear to result from spontaneous recovery, a complicating factor in evaluating treatment efficacy in children, as pointed out by Yairi in his chapter. Onslow and Packman note that the actual mechanism by which their treatment approach affects change is unknown, and may rest on a number of factors, including broad changes in the child’s interactions with parents in the home environment, as well as parents’ skill in identifying and correcting stuttering. Having found a technique that appears to work well for children who are in the initial stages of the disorder, Onslow and Packman plan to conduct additional research on the central agents of change, an excellent example of bridging a clinic–research gap.

Although adults may use response-contingent feedback to refocus their fluency-enhancing efforts, it is unclear how untutored children might do the same. James, Ricciardelli, Rogers, and Hunter (1989) noted that adults without fluency-shaping knowledge were much less likely to show positive responses to operant treatment of stuttering, a pattern reversed by providing the missing therapeutic experience. What mechanisms will eventually account for very young children’s apparent responsivity to operant programs such as Lidcombe? Such issues are far from academic: Maximizing the effectiveness of existing programs will require us to understand which components produce the optimal gain, and why.

As we bring this volume to a close, perhaps no two chapters take a more diverse perspective on stuttering research and treatment efficacy research than do Ingham and Cordes, and Starkweather. Ingham and Cordes clearly feel that the field is losing its scientific roots, and detect a trend for clinicians to ignore published outcome and speech production data. Few therapeutic recommendations or programs discussed in a recent journal issue devoted to stuttering treatment escape their critical analysis. There were conference attendees who felt their examples were poorly chosen, because contributors to that special journal issue were given the charge to provide tutorials rather than data-based experimental reports.

Nevertheless, the fact that clinicians appear to gravitate toward certain intervention approaches at the expense of others merits careful consideration. Others (Ryan & Ryan, 1996) have similarly lamented the relative unpopularity in the United States and Europe of operant approaches to stuttering treatment, for example, approaches that have clear documented success in experimental as well as in some clinical environments. Ingham and Cordes contend that clinicians are blind to efficacy data. Yet, most of the clinical efficacy data they cite relate to approaches that focus on reducing the frequency of stuttering to some minimal level. In Manning's view, this is akin to treating only the surface structure of the disorder. Starkweather amplifies this perspective by saying that most efficacy studies in stuttering only address what is an observable, measurable manifestation of the disorder and that a reduction in stuttering alone is not enough to define therapeutic efficacy, particularly if what is created (or neglected in treatment) is a host of undesirable avoidance reactions that go unnoticed. More important, Starkweather contends that before we can claim that a treatment is effective we first have to agree on what we mean by effective, a comment that by the end of the volume, has echoes in almost every chapter.

The second half of Ingham and Cordes' chapter tackles a very different but equally important question. When is therapy for stuttering in children warranted? Recent discussion, stemming primarily from Yairi and colleagues' work (see chap. 4, this volume, and Curlee & Yairi, 1997; Yairi & Curlee, 1997), has highlighted an old debate about whether therapy for very young stuttering children should be deferred until after a given length of time since onset of symptoms has passed. Because a significant number of children who stutter will recover, many within a year to 18 months after their first symptoms appear, Yairi and his colleagues question the efficacy, cost efficiency, and ethics of providing therapy to a group of children in which up to 80% will recover seemingly without intervention. Moreover, they question whether delaying intervention for those who do not spontaneously recover impairs the effectiveness of therapy given later.

Such proposals clearly disturb Ingham and Cordes, who present data to suggest that older children do not respond as favorably to therapeutic intervention as do younger children. Delaying therapy appears to have its costs for the individual child, whether or not other children might receive services that might have been unnecessary if clinicians had crystal balls capable of predicting individual, rather than group outcomes. The question of whether therapy provision is warranted, even to children who might recover at some later point without clinical assistance, is also an important concept to contemplate (Bernstein Ratner, 1997a, 1997b). In medical models, solving a problem sooner than later is rarely viewed as problematic: As a trivial example, headaches will go away by themselves, but people usually prefer to treat them with aspirin for quicker results. Moreover, Ingham and Cordes' discussion of the lowered outcome results for treating older children suggests the possibility that persistence of symptoms over time causes changes in stuttering that make it less tractable to intervention. Whether such changes are behavioral (such as increased habit strength of certain speech behaviors), cognitive, affective or an interaction of all three is not clear. What is clear is that we need properly

designed, ethical studies to test the merits of early intervention, and the costs of delaying such intervention. As Ingham and Cordes suggest, retrospective analysis is one approach to answering these questions. Unfortunately, prospective studies will become increasingly difficult to design as new information statistically linking chronicity of childhood stuttering to specific diagnostic factors, such as family history, language function and gender, emerge. As we better understand risk factors for recovery and chronicity, how does one randomly assign children to treatment decisions?

A related question is how one determines when “therapy” begins for stuttering, if parental advisement or environmental manipulation are part of a clinical approach to ameliorating the symptoms of early stuttering. Although not addressed in Ingham and Cordes’ chapter, other contributors (e.g., Hill and Gottwald) clearly advocate interventions that are not carried out by speech-language pathologists within the clinical setting. Such recommendations are subject to many of the concerns voiced by both Ingham and Yairi, but carry with them additional problems for scientific investigation of the effectiveness of or need for early intervention. In today’s electronically linked and increasingly literate world, it is clear that many parents will employ strategies that are advertised as home-based approaches to stuttering treatment. How such unmonitored parental responses will complicate evaluation of the merits of such recommendations and the outcomes of other treatment recommendations/procedures is not easily measurable, but will complicate outcome investigations of childhood stuttering.

Starkweather’s position on the merits of strengthening scientific research into the nature of stuttering and its most effective treatment is directly opposite to that of Ingham and Cordes. He offers a number of criteria for determining whether or not a question legitimately falls within the domain of scientific inquiry, and concludes that the highly variable nature of stuttering, particularly as it evolves over a person’s lifetime, makes it peculiarly unsuited to scientific inquiry. In particular, many clinicians and persons who stutter will resonate to the self-reference problem Starkweather discusses. At least part of the disorder of stuttering is a result of reactions to the primary behaviors that characterize it. Because such reactions distance us from the understanding of the primary underlying deficit, and because they infinitely complicate and individualize the behavioral characteristics of the disorder, Starkweather is pessimistic about our ability to gain deep insight into stuttering using the scientific method. From his perspective, much of what can be determined empirically about stuttering treatment has no relevance to whether or not treatment is effective — it is the client who is the ultimate judge of whether recovery from stuttering has been achieved. In this regard, he is most similar in his approach to Riley, who asks her clients to define the efficacy of their treatment.

In conclusion, the chapters in this volume paint a broad picture of research and clinical practice in stuttering. Although it may be debatable whether a gap exists between clinical and empirical science in stuttering, there is clear consensus that stuttering is a highly variable, multidimensional disorder. Even as we struggle to understand how stuttering emerges and what the proximal cause of the “first stutter” is, we are increasingly aware that being a stutterer shapes and changes the

behaviors we call stuttering. This phenomenon creates great challenges for researchers and clinicians alike. Stuttering produces negative affective, behavioral, and cognitive behaviors, some of which may have their roots in tangible neurological and psychological consequences to living as a person who stutters. The experience of speaking disfluently, with effort and with fear, may well create the intriguing new images of distinctive speech processing observed in recent neuroimaging studies of adults who stutter, rather than telling us important things about the cause of stuttering. More research needs to be done with children who stutter and recover as well as with those who show resistance to our behavioral methods for treating the disorder. The gap between researchers and clinicians will continue unless we all take a new look at how we conceptualize the disorder, how we conduct our empirical studies, and how we define "successful outcomes." This is our collective challenge for the future. It is one we believe that the field can meet successfully.

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2 The Best Day to Rethink Our Research Agenda Is Between Yesterday and Tomorrow

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This chapter won't help me win any popularity contests. Stuttering theory and therapy, in my opinion, have seldom remained flipped when they could just as easily have been flopped. At times, the windshield wiper has served as the main model for much of the theory and therapy development regarding stuttering. To highlight these fluctuations, a little bit of history is in order.

THE U.S.S. FLUENCY

To paraphrase that famous speech-language pathologist, Bob Dylan (1965), individuals who research stuttering "...don't need a weatherman to know which way the wind blows." Tacking between the shores of nurture and nature, and all points in between, has sailed our good ship that I will dub the U.S.S. Fluency. This vessel, often personned by a theoretically whipsawed crew, displays the dings and dents of a ship that has repeatedly sailed through heavy theoretical seas, and has been becalmed more than a few times by no significant differences.

Aboard ship, the ship's crew du jour, good people, straight and true, exhibits the confidence of those that think they can, and here I quote Professor Dylan again, (1965a), "do what has never been done, that can win what has never been won." Unfortunately, our stalwart crew, anxious to get the cruise underway, is sometimes guilty of leaving the harbor just a little too soon, without taking the time to adequately read the ship's logs from previous voyages. So, typically focused on their own journey, our crew frequently sets sail possessing an unhealthy disregard for the past, and thus, often remains doomed to repeat it. Chanting the sailing mantra, "She'll never go down," a catchy phrase one crew member took to heart after seeing it scrawled on the side of a passing iceberg, ship and crew confidently sail right into the path of theoretical hurricanes and therapeutic sand bars, if not the scientifically rudder-snarling effects of nonsignificant differences.

Sailing From Hot Topic to Hot Topic

Setting a course, sometimes seemingly modeled after an arcade game, our vessel pinballs along, here unloading passengers who weary of the voyage, there taking on new ones eager to "get it on" for science and Van Riper, not to mention promotion and tenure, discarding old equipment like a stripper, gathering new like a shop-til-you-dropper, and catching up on the mails in the form of journal publications. In essence, our crew gradually comes to discover that buggy whips, hula hoops, spats, and DAF don't garner market share quite the way they did when they and their ship first left port.

Oh sure, a mutiny occasionally occurs aboard ship, and the ship's steering wheel is personned by young turks and turkettes, but by and large, the crew gets a little older, a bit sea worn, and sort of fed up with the food on board. So, it is little wonder that our crew quickly disembarks when arriving at a new port (read theory). This permits a new crew to come aboard and set sail in search of theoretical booty. Of course, our new crew, much like our old crew—new and old often restricting their ship-to-shore communication to semaphore (better known as yearly poster sessions at national conferences)—has a less than adequate understanding of or concern with the ship's past voyages. In brief, some of our crew has little concern for realities other than their own. Thus, our ship—that sometimes appears more flagging than flagged—sets off again, bound for glory, which, unfortunately, routinely takes off without a forwarding address just before our ship arrives.

Charting a More Purposeful Course

What can be done to encourage our ship to sail in a less pinball-like, more programmatic fashion? Of course, I have no definitive midcourse corrections—true waffle artist that I am—but I think I have met the enemy and he or she looks a bit like thee and me. Without doubt, our stalwart ship will always cruise the uncharted seas of speculation, occasionally spotting islands of facts, and from time to time will land on some solid point of data. And try as we might, it is quite difficult, a priori, to influence the motion of the theoretical ocean. We can, however, build a bit more adaptable ship, and more often rig and sail it in the most efficient, consequential, and productive way possible.

What would be some of the instructions I'd give the crew of such a ship? Well, the following pearls of nonwisdom are submitted for the present as well as future crew's consideration. No, dear readers, you are not about to enter the theoretical twilight zone. Furthermore, this is not a "my way or the highway" manifesto. But I may be a bit strong in my criticisms and suggestions.

Sailing Instructions

Basically, my four-part sailing instructions (i.e., main message of this chapter) are:

1. Eschew "grind-to-find" research (i.e., throwing out a large net of unmotivated variables, hoping to drag something in with the tide of results) of any kind, but particularly regarding the disability of stuttering.
2. Stoke up the theoretical fires that underpin and permit testing of possible sources of impairment.
3. Ask not what treatment efficacy research can do for you and your program but what you and your program can do for treatment efficacy research.
4. Bring the handicap of stuttering out of the closet, let the sun shine on it, and be not afraid to objectify it.

CATALOGUING OF FACTS DOES NOT NECESSARILY CREATE A KNOWLEDGE BASE

Clearly, if one is to make an omelette, some eggs are going to have to be broken. To begin, let's crack open the product of our collective researches, past and present. What do we find? By and large, a stunning array of facts, a literal cornucopia of data spilling forth seemingly without end. Truly, our cup runneth over with facts. However, such research typically reflects, no matter how elegant, no matter how carefully done, no matter how novel the findings, a mere cataloguing or description of facts. Granted, the influence and significance of past as well as present descriptive research can and should not be disregarded. It has informed us tremendously about the disability of stuttering. Indeed, we owe a great deal to those who have informed us about the disability of stuttering. These facts represent our unique and important contribution to the knowledge bank, from which we all withdraw. Is there more to learn about the disability of stuttering? Absolutely, but what I'd like to advocate, at this time, is charting a course backwards—into full-blown theory development and testing—as well as forward—into objectification and documentation of the handicap of stuttering as well as the efficacy of our treatment for stuttering.

Some Principles to Guide Us

Ideally, our research should flow from ideas about reality, rather than simply describe, catalog, and categorize reality. I mean, we could, if we wanted to, count the number of trees with leaves of a certain shape and report that. But why? Far better, in my opinion, to have a theory that the durability of leaves in wind is affected by their shape, and then test that theory out, in a wind tunnel, with different shapes of leaflike objects and see which leaves last longer than others without shredding, and so forth. Both approaches—description versus theory-driven hypothesis testing—provide us with information. However, the latter goes one step beyond by providing us with *insight*, an enhanced, expanded understanding of the mechanism(s) that create, influence, and so forth, such information. Furthermore, like collagen in a bone-fusion operation, such theory-driven insight provides the bridge on which further information can be gathered and the means by which our field's knowledge base can be expanded and refined.

It is not only theory-driven, hypothesis-testing studies of *impairment* that are needed. We also need studies that relate to the *handicap* of stuttering as well. Although our profession and those related to it need and want to understand the impairment, the public we serve often wants to know and is vitally interested in the handicap. Indeed, it is probably safe to say that it is at the level of handicap that most people who stutter come to most acutely feel and experience the disability of stuttering. Consequently, the need for careful, controlled and objective study of the handicap of stuttering is of paramount importance.

Changing a Disability Does Not Necessarily Change a Handicap

For example, many studies of treatment with adults who stutter strongly suggest that prolonged, slow speech is most effective in terms of behavioral change. That's

great, that's fine, that's wonderful. However, what about the effects, if any, of such treatment on the handicap of stuttering? Do the people who stutter who receive such therapy feel, think, or act as if they are less disadvantaged academically, emotionally, psychologically, socially, or vocationally? Unfortunately, this seemingly solid fact (i.e., that prolonged, slow speech increases fluency) has all too often been taken as advice on what brand of therapy to buy. Yes, it is very reasonable to feel, think or believe that improvements in stuttering, the behavior, the disability, lead to improvements in the handicap of stuttering. But how firm is this belief, what is the quantity and quality of data upon which these beliefs are based? What evidence do we have that reduction in the frequency of stuttering, in and of itself, leads to reductions in the disadvantages of stuttering, be they vocational, academic, social, and so forth?

It is clear, changes in one (disability) is related to reductions in the other (handicap), but how and to what degree? For example, can we say to an individual who has just made a significant change/reduction in their stuttering, "You will feel, perceive, and experience no disadvantages stemming from stuttering, from now on, in any aspects of your life"? If we are going to operate from a basis of knowledge all the time, not just when it suits us, then I think a truthful answer to my question has to be as follows: "We do not know enough to unequivocally tell a person who has just significantly reduced the frequency of their stuttering that there will be no further disadvantages in their life related to their stuttering." For now, however, let us turn our attention away from what we don't know, to that which we do know and how we might know even more, in a more reliable fashion.

In the space allotted for this chapter, I really can't, even if I knew, tell you all that we have learned about stuttering from research. I can tell you, however, where I believe that more research seems to be needed and how we might go about meeting that need.

THREE LEVELS OF A DISORDER: IMPAIRMENT, DISABILITY, AND HANDICAP

To provide a framework for addressing these research needs, I would like to quickly review the three levels of any disorder (Curlee, 1993; Prins, 1991; Yaruss, 1988). The first level, *impairment*, involves, in essence, the cause(s) of the disorder; one example of research conducted in this area might be PET scans of cortical activity during the speech production of people who stutter (e.g., Fox, et al., 1996). The second level, *disability*, involves the behavioral manifestations of the disorder. An example of research conducted in this area might be a tabulation of the frequency of stuttering behaviors during the speech of children who do and do not stutter (e.g., Yairi, 1997). The third, or *handicap*, level of the disorder involves the disadvantages (of any kind) imposed by the disorder. One example of research conducted in this area might be the administration of the Inventory of Communication Attitudes (Watson, 1988) to assess how individuals who stutter believe and/or feel their problem has influenced their personal and/or professional lives.

Again, using these three levels of disorders as a frame, we can quickly examine what research has taught us. First, as I've said before, and as a quick review of our

textbooks (e.g., Bloodstein, 1995) will show, we have an amazing amount of information pertaining to *disability* (i.e., what stuttering sounds like, looks like, etc.). The quantity and quality of this information is, to borrow a popular phrase, “awesome.” Unfortunately, this large repository of information is not always well appreciated by those inside as well as outside the fields of speech, hearing, and language. Why? I believe this is because, despite our valiant attempts to understand impairment, much of what we have actually come to understand is disability. Although it is true that we have islands of facts about impairment (i.e., cause), many of these facts are surrounded by a vast sea of speculation. Further, we have seemingly taken for granted that the disability (e.g., frequency of stuttering) is identical conceptually to the handicap. Of course, it is difficult for someone to experience the handicap of stuttering without the disability of stuttering, but the disability does not necessarily circumscribe or define the handicap. Indeed, the subjective feelings of disadvantage surrounding the behavioral manifestations vary widely in number and nature.

As mentioned earlier, we are, for example, relatively clueless with regard to how our treatment of the disability of stuttering influences the handicap of stuttering. This is a state of affairs that must change for our treatment regimens to grow and be responsive to the entirety of the disorder of stuttering, not just to those aspects of the disorder that are externally observable and where numerically apparent changes are relatively easy to produce. Likewise, although many, many attempts have been made to document *treatment efficacy* for children, teenagers and adults who stutter (e.g., Blood & Conture, 1998; Conture, 1996; Ingham, 1993), considerable uncertainty remains, regarding, among other things (a) the appropriate definition of success (short-, medium-, and long-term) and (b) the most pertinent dependent variables to measure.

What is needed? Well, to answer that, we have to briefly consider how knowledge, in any field, is developed, tested, and refined.

DESCRIPTION, MODEL, AND THEORY: BUILDING BLOCKS FOR ANY KNOWLEDGE-BASED PROFESSIONAL DISCIPLINE

Abstracting from Olswang’s (1993) coverage of this topic, there are three inter-related levels of science involved in the development of knowledge. The first (and most concrete) level, *description*, involves the cataloguing of all relevant behavior. As a hypothetical example, we could describe all the semantic, syntactic, and phonologic correlates of instances of stuttering during conversation. The second level, *model*, involves the identification of principles that account for relevant behavior. As a hypothetical example, we could specify how the number and nature of clausal constituents in an utterance underlies or explains apparent correlations between phonetic, semantic, and grammatical elements seemingly associated with stuttering. The third level, *theory*, attempts to test a finite set of principles that concur with (or flow from) the model and, by so doing, reveals the mechanism or processes that account for the phenomenon under study. As a hypothetical example of theory, we might speculate that more cognitive/linguistic planning time is required

for longer and more complex clauses and, therefore, if planning time is truncated or interrupted (either externally or internally), the resulting overt speech should contain more errors and/or disfluencies. If we take these three levels—description, model, and theory—and apply them to the three aspects of a disorder (i.e., impairment, disability, and handicap), we may be able to more clearly specify what research has or has not taught us and what it still needs to tell and/or teach us.

IMPAIRMENT, DISABILITY, AND HANDICAP MEET DESCRIPTION, MODELING, AND THEORY

Modeling and Theorizing about Impairment

In terms of impairment, there is a clear need for theory development. Theory is the engine that drives organized, systematic, and motivated assessment of cause. Of course, the more practical reader might wonder: Why continue to study impairment, why continue to develop theories? My answer to this is that our field and our very livelihood may depend on it. If ours is a profession (and I think it is), it is supposedly based on or grounded in a body of knowledge. Such a body of knowledge should not be a mere collection of facts, something similar to a professional-knowledge version of a butterfly or stamp collection. Our body of knowledge needs to be developed, understood, and explained relative to underlying notions about what causes stuttering. Indeed, it is theory rather than fact that we most often rely on when responding to our clients, their parents, the press, and other professionals when they ask, “What causes stuttering”? In essence, a search for impairment is a search for one of the cornerstones of our profession.

Describing Disability

Although description of relevant behaviors may be of value to an understanding of the disability, only through theory will we uncover relations, underlying mechanisms and processes, and rule-governed phenomena associated with cause. We have already collected a great deal of information about disability. Of course, a great deal more needs to be known, but we really need to curtail mere grind-to-find research (i.e., research investigations that measure a large number of variables in the hopes that somehow, somewhere, something will turn up). Our descriptions of stuttering should be motivated by our notions of what we think causes stuttering and/or what we think may be contributing to the handicap of stuttering, and not merely gathering more data with which to further describe the disability.

Describing the Handicap

Stuttering, for someone who stutters, particularly as they grow older, involves more than just speech and speech-related behaviors associated with instances of stuttering. It involves handicap, or the disadvantages that relate to and/or result from the disability. To study handicap, we need to develop principles that may account for why stuttering and/or selected aspects of stuttering are perceived by stutterers and/or their listeners as disadvantages, as negatives. Here, we must not be afraid to be appropriately subjective, to uncover not only the overt surface