

Pioneering Stuttering Research in the 21st Century:

**The First Joint Symposium
for Scientists and Consumers**

June 26-27, 2002
Anaheim, CA

Summary Report and Proceedings



**National
Stuttering
Association**

We brighten the world for people who stutter

Pioneering Stuttering Research in the 21st Century: The First Joint Symposium for Scientists and Consumers

Summary Report and Proceedings

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Executive Summary

On June 26 and 27, 2002, the National Stuttering Association (NSA) gathered speech researchers, speech-language pathologists, and people who stutter for a “joint symposium” on stuttering research. The meeting, entitled *Pioneering Stuttering Research in the 21st Century*, was designed to encourage a dialogue between scientists and people who stutter regarding issues of importance in the study of fluency disorders. Participants worked in small groups to discuss a variety of topics reflecting current research priorities from across the field. Discussion topics included early intervention and identification of risk factors for developing stuttering, treatment outcomes research, relationships between brain functioning and speech behavior, attitudes toward people who stutter, and interactions between linguistic and motor factors in the development of stuttering. Each working group evaluated a series of questions about goals for future research and discussed roadblocks to achieving those goals. Through their discussions, participants identified several key areas where further research is needed and brainstormed about novel approaches for meeting those research needs. Among the many outcomes of the meeting was the initiation of several collaborations among research scientists, as well as new partnerships between scientists and consumers. These collaborations hold significant promise for improving the understanding of the stuttering disorder and the treatment of people who stutter. Less tangible outcomes include a greater sense of understanding of the disorder for people who stutter, clinicians, and researchers and an increased sense of partnership among these groups as they continue to work toward addressing research needs in the future.

Background: Research on Stuttering

The National Stuttering Association (NSA) is the largest support group organization in the United States for people who stutter. The mission of the NSA is to bring hope, dignity, support, education and empowerment to children and adults who stutter. The organization seeks to fulfill this mission through a broad vision statement outlining several key priorities for improving the lives of people who stutter. This vision includes activities designed to develop innovative programs for reaching out to people who stutter, as well as activities designed to support research on the causes and treatments for stuttering.

For decades, the study of fluency disorders has been a prominent area within the broader field of speech-language pathology. Many of the first speech-language pathologists were people who stuttered who were interested in the scientific evaluation of this often misunderstood communication disorder. Over the years, researchers have sought to examine many different aspects of the etiology and phenomenology of stuttering, including the surface characteristics of stuttered speech, the factors that influence stuttering in real-world speaking situations, and the similarities and differences between people who stutter and typically fluent speakers. Studies have also examined various approaches to treating the disorder, though philosophical differences about the nature of the disorder and the goals of treatment have hampered the development of consensus definitions and universally agreed-upon treatment strategies.

A number of meaningful advances in the understanding of stuttering have accumulated through the years. Today it is widely acknowledged that stuttering is affected by multiple, interacting factors—stuttering is no longer believed to be caused by a single factor such as a psychological disorder or a tic. Stuttering, which generally begins in early childhood, is widely believed to arise in part due to as-yet-unspecified genetic factors affecting the development of speech and language, working in combination with various influences from within a child's environment. More specifically, the aspects of a child's development that are believed to contribute to the production of

speech disfluencies include the child's motoric ability for moving his mouth and coordinating the parts of the body involved in speaking, as well as the child's linguistic ability for formulating language and planning the various components of a message. Particular attention has been paid in recent years to the possible interactions between the child's linguistic and motoric skills, though the precise relationship between these aspects of communication is not well understood.

Increasingly, there has been a focus on studying the development of young children, since the disorder generally appears between the ages of 2½ and 5 years. Although many children may begin to exhibit speech disfluencies during their early development, the majority of those children will go on to develop ostensibly normal speech fluency. The causes of the early development and frequent resolution of stuttering without intervention are not well-understood, and there is no reliable means for differentiating those children who are at risk for developing chronic stuttering from those who are likely to develop more fluent speech (either on their own or as the result of treatment). Thus, there is a significant and often contentious debate within the field about the appropriate timing for early intervention and about which children should receive such intervention.

In recent years, advances in technology have allowed direct imaging of brain functioning during fluent and disfluent speech, as well as the assessment of neurotransmitter levels in different regions of the brain in people who stutter compared to people who do not stutter. Findings point to some relatively consistent differences between fluent and disfluent speakers, suggesting that these functional neurological differences may contribute to the development of stuttering. Because these studies have only been conducted with adults, however, it is difficult, if not impossible, to determine whether the findings reflect a potential cause of stuttering or if they are the result of a lifetime of living with the disorder. Nevertheless, results do indicate that there are meaningful differences in neural functioning between people who stutter and people who do not stutter, at least during those times when speakers are producing disfluent speech.

Although there have been improvements in the understanding of stuttering, there is still a considerable degree of misinformation among the lay public about the nature of stuttering. Surveys reveal that many people believe that stuttering is simply a learned behavior, the result of nervousness or anxiety, or possibly the result of unidentified brain damage. These hypotheses are not supported by current research, though these and other beliefs persist in society. It is likely that these inaccurate and stereotypical opinions about stuttering contribute to negative societal attitudes toward stuttering and people who stutter. Furthermore, many people appear to hold a number of erroneous beliefs about appropriate treatments for stuttering, with a large percentage of the population believing that it is best not to address stuttering in young children, even though numerous studies have demonstrated that there are benefits to early intervention.

Unfortunately, these inaccurate beliefs about the causes and treatment of stuttering are held not only by the lay public; they are also held by a majority of practicing speech-language pathologists, the health professionals who are supposed to be trained to diagnose and treat children and adults who stutter. As a result, stuttering specialists and people who stutter face a major impediment when they seek to reduce negative attitudes about stuttering among the general public.

In sum, there are a number of significant challenges facing the field of fluency disorders. These issues range from lingering uncertainties about the etiology of the disorder to a lack of consensus about treatment practices to a pervasive misinformation among professionals about the current understanding of stuttering. These concerns have become particularly relevant in recent years. As the scope of practice within the field of speech-language pathology has grown, the study of stuttering—once so central to the field—has been marginalized. University training programs that formerly specialized in stuttering have now dropped stuttering from the curriculum or reduced it to the status of an elective. Researchers who built careers around stuttering have retired, but they often have not been replaced by new faculty specializing in stuttering. The volume of studies on stuttering published in peer-

reviewed journals has also diminished. Finally (and perhaps most importantly, from the perspective of people who stutter), because of these reductions in training and research, the number of clinicians who are qualified to provide appropriate treatment to people who stutter has declined dramatically.

Seeking Solutions

In recent years, some have argued that solutions to these problems are not likely to come from within the professional community, in part because of the broad scope of practice within speech-language pathology, and in part because of the small number of academic and clinical faculty specializing in stuttering. To be sure, there are clinicians and researchers within the professional community who are strongly advocating for increased resources for stuttering, though they appear to face an uphill battle. At the very least, it is clear that these professionals will require assistance if they are to successfully meet the challenges facing the field of fluency disorders.

The National Stuttering Association has a vested interest in ensuring the future of research in the field of fluency disorders. People who stutter deserve appropriate treatment for their communication difficulties, and this will only come through further advances in research. Thus, because of its vision of supporting research on the nature of stuttering and fostering improvements in the treatment of stuttering, the NSA seeks to play a key role in supporting research on stuttering.

There are a number of meaningful ways in which the NSA can support research. For example, the organization's membership represents a large group of people who stutter who may wish to serve as subjects in research studies. People who stutter can also provide a helpful guide for scientists regarding research topics and questions that are relevant to the population the profession is seeking to serve. In order to achieve these goals, however, it is necessary to initiate and develop an open dialogue between professionals (researchers and clinicians) and consumers (people who stutter and their families) to facilitate collaboration and partnership to support stuttering research.

The National Stuttering Association's Research Committee

Recognizing the importance of increasing connections between researchers, clinicians, and people who stutter, the National Stuttering Association created a Research Committee (NSARC) dedicated to supporting research on stuttering and facilitating interactions between the professional and consumer communities. The membership of the NSARC includes a chair (a member of the NSA's board of directors and chair of the professional relations committee) as well as 3 consumer representatives (people who stutter) and 3 professional representatives (nationally recognized scientists who specialize in stuttering research).

The NSARC reviews research proposals submitted by scientists interested in partnering with the NSA to ensure the safety of the membership and to support researchers in contacting and recruiting potential research participants. Since its creation in 1999, the committee has reviewed more than 20 proposals, and several of the studies have resulted in publications submitted to peer-reviewed journals on communication disorders. In addition to facilitating research for specific studies, the NSARC has also sought to promote stuttering research by increasing awareness among both consumers and professionals about the importance of research and about key problems facing the field. Finally, the committee has completed projects of its own, and two studies examining the treatment and support group experiences of NSA members were recently published in the *Journal of Fluency Disorders*.

Facilitating Collaboration: Goals for a Joint Symposium

Each year, there are numerous regional, national, and international conferences at which researchers and clinicians in the area of fluency disorders can come together to discuss current research projects and future research needs. Examples include the annual convention of the American Speech-Language-Hearing Association (ASHA), which draws approximately 10,000-12,000 speech-language pathologists. More specific to fluency are the annual Leadership Conferences hosted by ASHA's Special

Interest Division for Fluency Disorders (DIV-4), the World Congresses held by the International Fluency Association (IFA), and the Speech Motor Conferences hosted by the University of Nijmegen. The stuttering support community also has the opportunity to gather to discuss stuttering and stuttering research at the annual conference hosted by the National Stuttering Association.

In recent years, there has been a growing overlap in the attendance at these meetings, with an increase in the number stuttering support group members attending conferences aimed primarily at professionals in fluency disorders (particularly the DIV-4 leadership conference), and a dramatic increase in the number of professionals attending annual NSA conferences. Although this interaction among scientists, clinicians, and consumers is widely hailed as a positive step in uniting those interested in the study of fluency disorders, there is much work to be done. Researchers still express an interest in increasing their opportunities for interaction and collaboration with other researchers, and they continue to express concerns about the need for research participants. Meanwhile, people who stutter still express the concern that they do not have enough input into the research that is conducted on the disorder that affects their lives on a daily basis. All of these parties are expressing a desire to have greater interaction with one another, but they lack a mechanism for accomplishing this important goal.

In an attempt to address these concerns, the NSA decided to host a new type of research conference that was specifically designed to facilitate collaboration between and among individuals interested in fluency disorders. Ideally, such a meeting would bring individuals from various segments of the field together for a symposium focusing on how these parties could work together to improve the body of knowledge about stuttering. Thus, it was determined that the specific goals for this conference would be: (a) to identify research needs in various areas of the study of stuttering, (b) to develop approaches for addressing those needs, (c) to facilitate collaboration between researchers and consumers, and (d) to facilitate collaboration among researchers.

Symposium Attendance

The symposium was designed to attract scientists conducting research on stuttering, clinicians with a significant interest in stuttering and access to potential research participants, and people who stutter who had previously expressed an interest in participating in a dialogue about stuttering research. In total, approximately 60 people attended this first-ever symposium with a ratio of approximately 3 clinicians or researchers to each consumer (person who stutters). A complete list of participants is included in Appendix A.

Symposium Structure and Agenda

Because the focus of the symposium was to facilitate interaction and encourage collaboration on a variety of topics, it was determined that it would be most beneficial to employ an open format in which participants would be allowed select which topic they would address in their working groups. Thus, unlike prior working conferences on stuttering, participants were not assigned to specific discussion groups. Instead, they were encouraged to select topics of interest to them, or create working groups on new topics if they desired, so they would have the opportunity to meet with others with similar interests and concerns.

It was anticipated that some of the most productive discussions would take place in individual or small group interactions that occurred during or between scheduled meeting times. Thus, the symposium was structured to allow ample time in working group meetings to facilitate interactions between participants. The meeting also included plenary sessions so participants could receive updates about other working groups. The schedule included time for informal interaction so participants could continue discussions on topics raised during the meeting. The complete agenda for the symposium is included in Appendix B.

Initial Working Group Discussion Topics

Prior to the symposium, group leaders and recorders were recruited to facilitate the working group discussions. It was anticipated that the discussions in all groups would be far-

reaching and that participants would address a variety of relevant issues, regardless of which topic they set out to discuss at the start of the meeting. Indeed, one of the implicit goals of the small group discussions was to incorporate and integrate a broad range of topics. Thus, leaders were encouraged to facilitate the inclusion of many different areas and points of view throughout the group discussions.

To focus the working groups on key issues facing the field, the Steering Committee developed an initial list of group discussion topics. As noted above, participants were encouraged to join any group that was of interest to them, and they were allowed to switch groups or create new groups as needed so they could discuss new topics not being addressed in other groups. Following are the initial discussion groups proposed by the Steering Committee:

Treatment Outcomes. Designed to explore outcomes research from a variety of perspectives, based on different approaches to stuttering treatment. Suggested topics included: ideal outcomes of treatment, strategies for measuring outcomes, difficulties with assessment, and future needs for outcomes studies.

Language & Motor Interactions. Designed to explore the interaction between language formulation and motoric execution in the production of disfluencies and the development of stuttering. Suggested topics included various aspects of language planning (e.g., syntactic and phonetic complexity) and speech production (e.g., speaking rate, pausing), differences between people who do and do not stutter, and current theories of stuttering.

Brain & Behavior. Designed to explore the complex relationships between brain functioning and speech behavior. Suggested topics included: relationships between fluency and neural structure/function, brain imaging and other methods of assessing neural function, and effect of speaking situations or medications on brain function and fluency.

Attitudes toward Stuttering and People Who Stutter. Designed to explore research on public attitudes toward stuttering, including the attitudes of speech-language pathologists and others who have an impact on people who

stutter. Suggested topics included: methods for measuring and assessing attitudes, strategies for increasing public awareness, and ways of changing attitudes within key populations.

Risk Factors / Early Intervention. Designed to explore research on risk factors that may contribute to the development of stuttering and the influence of these risk factors on treatment recommendations for preschool children who stutter. Suggested topics included: genetic and environmental factors influencing the development of stuttering and ways of assessing the value of early intervention.

Participants were provided a series of key questions about the future of research in fluency disorders to focus and guide the working group discussions. As noted above, it was anticipated that the groups would address topics beyond these original questions; the questions were simply used as a starting point to facilitate discussions and to provide some structure to the sessions. These initial working questions included:

- What are the key research questions in this area?
- What is currently being done to address these questions?
- What are the needs for additional research to address these questions?
- How can the identified current and future needs for research in this area be met?
- What are the roadblocks to meeting these needs?
- What collaborative and other strategies can be developed to overcome these roadblocks?
- What action plans, based on new and existing models of funding and collaboration, can be developed to generate needed research in this area?
- What roles can consumer organizations play in these efforts?

Using these questions as a starting point, working groups began to discuss the future of stuttering research and to develop collaborations designed to meet research needs across the field.

Working Group Outcomes

Because working groups were encouraged to “follow their own lead” in discussions about current research issues, a wide variety of topics were addressed. Many of the discussions initiated at the symposium continued after the meeting through additional interactions among the participants. As a result, it is difficult to provide a concise summary of the outcomes of the symposium. Nevertheless, following are brief overviews of the outcomes of each working group’s discussions. These summaries, which are based on the notes prepared by group recorders during the symposium, were reviewed by the group leaders to ensure that they captured the essence of the discussions:

Treatment Outcomes. From the outset of the meeting, it was apparent that symposium participants had a significant interest in discussing research on stuttering treatment outcomes. The treatment outcomes group was initially the largest of the 5 discussion groups—too large, in fact, to allow for the type of informal interaction and discussion the group leaders were seeking. As a result, the treatment outcomes group was immediately split into two sections, with a second group leader and recorder selected from among the participants in the group. The decision to split the group turned out to be fortuitous, for the two sections of the outcomes group each went on to discuss different but related aspects of treatment outcomes research on stuttering.

Group 1. One section of the treatment outcomes group focused primarily on the *assessment* of treatment efficacy, with a detailed discussion of what constitutes successful treatment and how this can be reliably measured by researchers conducting research in this area. Indeed, one of the key issues facing the field of fluency disorders is precisely *which* treatment approaches are most helpful for people who stutter. The field has long been faced with a rather strict division between treatment approaches, with some therapies focusing primarily on helping people speak more fluently (through techniques designed to change the way the person speaks) and other therapies focusing on a broader set of goals that may include increased fluency in addition to improved attitudes toward speaking and

stuttering, reduced tension and struggle during both fluent and disfluent speech, and increased communication abilities. Of course, many clinicians and researchers combine these philosophies into an integrated or eclectic approach; however, treatment gains are still frequently discussed in terms of changes that are related to “speech modification” or “stuttering modification” therapies.

The group reflected on the fact that the debate is not based purely on different beliefs about the disorder, for the advocates of fluency-based treatments have amassed a considerable body of data demonstrating that it is possible to increase speakers’ fluency. This stands in stark contrast to the published research base that is currently available to support broad-based treatments, which is minimal at best. Still, the majority of the participants in this group voiced strong opinions about treatment outcomes research and, in particular, about the difference between those aspects of change that may be easily measurable but not especially relevant to a person’s life and those aspects of change that may be difficult to measure but are extremely relevant to a person’s ability to communicate and overall sense of well-being. The imbalance in available treatment outcomes research has led some clinicians and researchers to make some fairly strong claims about which approaches should to be applied in the treatment of stuttering, and this has increased the intensity of the debate. In fact, the tenor of the debate itself was identified as one of the main roadblocks to furthering outcomes research and improving knowledge about stuttering treatment outcomes.

As a result, one of the key research questions about stuttering treatment outcomes that was discussed by this group was: do those treatment approaches that focus on a broader set of goals actually help people who stutter? Related discussion addressed the nature of the improvements clients may exhibit, in terms of increased fluency, modified stuttering, improved attitudes, and enhanced communication abilities. Participants discussed how these changes might be meaningfully documented through research. The majority of the group’s discussion time then focused on identifying and developing ways of assessing treatment outcomes across a variety of relevant domains.

Current research efforts in this area that were reviewed included the development of a new instrument for evaluating changes in the impact of stuttering on a speaker’s life. Specific domains examined in the instrument include: the speaker’s reactions to stuttering, her functional communication abilities, and overall quality of life. The group determined that one of the key strategies that could be employed to further the study of stuttering treatment outcomes would be for research centers to collaborate in the use of some type of consistent measurement protocol for assessing the changes clients experience in different treatment programs around the country.

Other important aspects of outcomes measurement were also highlighted, including: the rhythm of speech (including smoothness, pauses, rate of communication), the use of less-helpful strategies such as avoidance and circumlocution, and more intrinsic factors such as an increased feeling of control and a sense of confidence that speakers could say what they wanted to say at the time they wanted to say it. Other, less tangible aspects of success were also discussed including the extent to which a people’s lives are “ruled” by stuttering and how much their lives have changed even though they may continue to stutter.

During this discussions, researchers developing a measurement instruments for evaluating the outcomes of stuttering treatment initiated a new dialogue with clinicians who have access to large clinical populations. They discussed ways to work together to evaluate the value of the treatment program using these new, broad-based assessment procedures. This collaboration represents one of the many tangible outcomes of the research symposium that have the potential for improving stuttering research.

Finally, the group concluded that consumer groups such as the NSA could play a major role in further research on treatment outcomes in several ways: first, by demanding better access to treatment outcomes data; second, by supporting research efforts through participation in ongoing and future studies of treatment outcomes; and third, by working to educate practicing clinicians about the need to carefully consider the results of the treatment approaches they employ.

Group 2. The other section of the treatment outcomes group focused on several related topics, including:

- The importance of considering the perspective of both the client and the family when conducting research on treatment outcomes
- The challenges associated with assessing clients' communication attitudes
- The value of considering personal stories and narratives when assessing outcomes
- The need to incorporate self-assessment in the treatment evaluation process

The discussion of these variables also led to a consideration of difference between the speaker's opinion and the observer's or clinician's opinion about progress in treatment. Several of the participants voiced concerns with some treatment approaches that are based solely on the clinician's observation. They also highlighted the fact that some treatment approaches may interfere with a speaker's sense of naturalness when speaking.

In addition, this group focused on other aspects of treatment outcomes research, such as:

- Techniques for measuring effective communication and ways to study various dimensions of effective communication, including quality of communication and effort involved in communicating
- Ways of evaluating the variability of stuttering in different speaking situations
- Method for tracking the nature of rate of relapse with various treatment models
- Decisions about how long and to what degree treatment gains should last in order for a treatment to be deemed "effective"
- Questions about how the variability of stuttering should be taken into account in outcomes studies
- Development of strategies for predictive assessment to determine which treatment goals and approaches would be most appropriate for a particular client

Most notable among these discussion topics was the consideration of speaker's *effort* and how the measurement of effort might be

related to treatment outcomes research. The group pointed out that producing stuttered disfluencies is normal for people who stutter and therefore does not require them to try to change their speech, while managing stuttering *does* require volitional effort. Thus, many treatment programs may actually require their clients to expend greater effort following treatment than before treatment. This may have a significant impact on the long-term success of those who participate in treatment, so effort should be measured as part of a comprehensive outcomes assessment strategy.

The group highlighted a number of key principles that should be applied when approaching outcomes assessment. Most notable was the idea that the measurement of outcomes should be independent of the specific treatment approach that was used. The importance of including clients in assessment and treatment decision-making was also highlighted. This led to an in-depth discussion of what messages people who stutter would like to hear from speech-language pathologists as collaboration in treatment and research is increased. Key topics that were emphasized included a more thorough evaluation of the goals of treatment, the feasibility of achieving completely "stutter-free" speech for many adults, the effect of treatment strategies on a speaker's feeling of control, naturalness, and effort, and the importance of measuring life changes rather than just fluency changes.

This group also discussed a number of roadblocks and challenges to treatment outcomes measurement. These included:

- Differences in client and family expectations for treatment
- A lack of consensus across the profession about the goals of treatment, definitions of success, and terminology used in various treatment approaches
- Difficulties clients, clinicians, and researchers may experience in knowing what they want, or changing what they want, from treatment and the pitfalls of measuring outcomes based on goals stated in the initial interview without taking into account the fact that those goals may change during the course of therapy.

- Differences in measurement instruments used during the treatment process and whether these measures can reflect the dynamic nature of treatment goals and expectations
- How clinicians, researchers, and consumers should respond to treatments with less than optimal outcomes, and how such programs should be identified

Finally, the group identified several strategies for overcoming these and other roadblocks. As with the other treatment outcomes group, recommendations focused on developing collaborations. Specifically, the group suggested that the NSA continue to support the dialogue between people who stutter, researchers, and clinicians. It was recommended that future meetings involve even more NSA members, including families and parents of children who stutter, as well as other related professionals. Other ideas included forming partnership with research committees in other stuttering organizations and continuing to pursue funding and support for research meetings.

The group highlighted the role that consumer organizations could play in advocating for research on treatment outcomes. Group participants pointed out that the NSA could play a role in collecting more information about people who stutter through narratives and bibliographies about people's experiences in life, in treatment, and in support. Finally, the group specifically suggested that groups such as the NSA could "rattle the cages" of professionals to encourage research on stuttering that met the needs of people who stutter and their families.

Attitudes toward Stuttering and People Who Stutter. The attitudes group addressed several issues related to the perception of people who stutter among the general public and among speech professionals. The group also examined the attitudes that are held by people who stutter themselves and the role these attitudes may play in shaping public opinion about stuttering. They emphasized the fact that the attitudes held by the general public, as well as the attitudes held by people who stutter, can play a significant role in determining the impact of stuttering on a person's life.

The group identified several key issues related to the study of attitudes, including:

- Public misinformation / misconceptions about stuttering and common stereotypes about people who stutter
- Thoughts, feelings, and behaviors that listeners might have in reaction to stuttering and speaking strategies
- The attitudes people who stutter have about their own stuttering and how this might affect listeners' attitudes
- The role of self-disclosure or acknowledgment of stuttering in influencing listeners' perceptions about stuttering
- The feasibility of changing public attitudes about stuttering
- Cultural differences in people's attitudes toward stuttering

In discussing public opinions about stuttering, they considered how "attitudes" should be defined and how these may be related to "feelings," "reactions," and "behaviors." They also considered the difference between changing attitudes and changing behaviors. The group wondered about *which* attitudes should be changed and which specific populations should be addressed (e.g., speech-language pathologists, particularly those in the schools).

A significant portion of the group's discussion was devoted to the question of *how* public opinions might be changed. The group recognized that providing education may not be sufficient to change attitudes. Thus, they discussed specific factors influencing attitudes, beginning with how public opinions should be measured, what factors might contribute to positive changes in public opinions, the role legislation might play in changing public attitudes, the individual speaker's role in self-advocacy, and how self-advocacy might lead to changes in public attitudes.

Participants noted that research on attitudes toward stuttering is already being conducted. For example, prior studies have established that the lay public does hold misconceptions and stereotypical beliefs about people who stutter (e.g., that people who stutter are nervous, that stuttering is a psychological

problem, that stuttering is just a habit, etc.). Current studies are seeking to document these beliefs across cultures and to examine specific factors that may contribute to listeners' perception of people who stutter (e.g., the amount of stuttering a speaker exhibits or whether the speaker acknowledges stuttering). Nevertheless, the group also highlighted a number of areas where additional research is needed. Specifically, the following "especially fruitful" areas of research were identified:

- Comparing attitudes of listeners before and after interactions with people who stutter
- Identifying specific strategies that people who stutter use to manage their stuttering via personal storytelling
- Comparing listener responses to various 'strategies' people who stutter might use to manage their stuttering, and examining changes in perception after people who stutter use those strategies.
- Interviewing the general public about stuttering and people who stutter
- Examining the *feelings* of people who stutter (distinguishing between attitudes and feelings) and studying how researchers could reliably assess people's feelings?
- Investigating interactions among the speaker's perceptions, reactions to the environment, and ability to manipulate the environment
- Examining how self-disclosure may affect a speaker's attitudes toward himself as well as the attitudes of other people

These areas of research were highlighted because the results from such studies would provide an understanding of the factors that influence attitudes toward people who stutter that would provide support for future attempts to modify and improve public attitudes.

Several roadblocks to conducting this type of research were identified, such as the fact that providing information about stuttering to the general public may not affect their attitudes about stuttering. Other roadblocks included difficulties with measuring attitudes and identifying representative samples in evaluations of public attitudes. Practical matters,

such as difficulties obtaining funding and the challenges of publishing qualitative research in journals, were also highlighted.

The group identified a number of strategies that may be employed to overcome these roadblocks. First, they highlighted the importance of consumer organizations in encouraging people who stutter to participate in research on public attitudes. One example involved having people who stutter partner with researchers to examine how changes in public attitudes may be associated with different types of interactions or disclosures on the part of the speaker (e.g., those who disclose that they stutter versus those who do not). Group members also stressed the value of educating individuals about stuttering through self-advocacy, "one person at a time."

Ultimately, the group defined a new research program that could be undertaken to evaluate the factors that influence public attitudes. A small group met during and after the research symposium to develop the plans for a series of studies that would manipulate different aspects of a speaker's interaction with a listener. (As will be discussed in more detail below, this collaboration represents one of the most important outcomes of the symposium, for it demonstrates that bringing researchers, clinicians, and people who stutter together in this fashion can help to further research on stuttering in a real and substantive way.)

Language & Motor Interactions and Brain and Behavior. After the first round of working meetings, the Language & Motor Interactions group and the Brain and Behavior group combined because of a significant overlap in their discussion topics. The following summary describes the outcomes of each individual group, as well as the discussions that took place after the groups were combined.

Language & Motor Interaction: At the beginning of the symposium, the *Language & Motor Interaction* group focused on current research on specific aspects of language planning and speech production that appear to contribute to the likelihood that children will stutter. Key research questions that were identified included:

- Do people who stutter have abnormal speech motor systems?
- Do people who stutter have abnormal language processing abilities?
- Do people who stutter have *both* abnormal speech motor systems and abnormal processing abilities?
- Do speech motor abilities and processing abilities interact?
- Can these factors explain stuttering?

In reviewing specific research being conducted by prominent scientists, the group reflected on the fact that motor researchers have primarily examined motor factors while language researchers have primarily examined linguistic factors. This is not surprising, of course. It is also not surprising that most researchers in both of these domains have found some factors that appear to distinguish people who stutter from people who do not stutter. Still, the group highlighted the fact that there are relatively few researchers who have examined both linguistic and motoric factors simultaneously.

The group also discussed the fact that there is a significant body of literature highlighting the ways that linguistic variables seem to be related to the production of speech disfluencies. For example, longer, more complex utterances are more likely to be disfluent. Still, such findings do not necessarily explain *stuttering*, suggesting that further research on these factors—and on the ways these factors might interact with motor variables—is necessary.

One specific need that the group identified was related to children's early differentiation between stuttering and disfluency. Specific questions included the following:

- Do young disfluent children recognize that their speech is different or that they are having difficulty producing speech?
- Is the difference between disfluency and stuttering related to the child's reactions to disfluencies and, by extension, to their temperament?
- Can studies of children's language and motor development be incorporated into studies of early treatment or early recovery?

- What changes occur in the speech or language development of children who recover from stuttering after treatment?
- What differences are seen in children who recover from early stuttering compared to children whose stuttering persists?

The group also identified several roadblocks to answering these and other research questions. One set of roadblocks was related to the scientists conducting the research. Since these studies require the integration of knowledge from a variety of different perspectives, then the scientists doing the research will either need to have a comprehensive knowledge of these different perspectives or they will need to collaborate with other scientists who have that knowledge. Without this collaboration, scientists will continue to look at this complicated disorder from different perspectives, in isolation, without getting a sense of the big picture. The group also pointed out that until recently, researchers had not formed collaborative partnerships with consumers. In some cases, such integration is beginning to happen; however, time, money, and differences in philosophy can limit collaboration. Furthermore, the growing shortage of researchers and doctoral students in fluency disorders limits opportunities for collaboration and further research. Finally, the group pointed out that instructors who focus on research in their classroom teaching may be subject to less positive student evaluations, thereby limiting students' exposure to research. This serves to further decrease the likelihood that students will gain an interest in research and develop careers as scientists.

Another set of roadblocks was related to the recruitment and retention of the young participants needed for this research. In order for researchers to examine changes in children's speech and language abilities close to the onset of stuttering, parents need to bring their children in for studies as soon as they notice that their child's speech is "different." Even if a child is successfully enrolled in a study, however, their participation may be truncated if the child's speech improves. Furthermore, the group commented on the fact that working with young children can be quite difficult. First, the

methods available for examining children's speech and language are limited to clinical tests and measures; advanced techniques such as brain imaging and certain motor tasks are not generally available. Also, the requirements for institutional review have become more strict in recent years. Though this is perhaps necessary and appropriate, the requirements still complicate the research process and increase the need for multi-center studies to obtain sufficient subject numbers. Finally, a more general research problem was noted. Because each subject is not studied by multiple researchers interested in the different aspects of stuttering, the relationship between various components may be obscured when different researchers examine different children. (The group used the analogy of building a puzzle with pieces from many different boxes.)

The group's suggestions for solutions to these and other roadblocks were addressed in the joint session with the Brain & Behavior group. These suggestions are summarized below.

Brain and Behavior group: The Brain and Behavior group started the meeting with a discussion of key research questions relating to the understanding of the etiology and nature of stuttering. Specific questions included:

- To what extent are the symptoms of stuttering learned or neurophysiologic?
- Is stuttering a disorder or a symptom?
- How do we differentiate neurophysiologic vs. experiential effects on brain imaging?
- How can we conduct relevant studies (including brain scans or genetics) in very young (30 months) children, pre-stuttering onset with follow-up

The group highlighted a number of specific needs that would support research on such questions, including:

- A "brain bank" to facilitate studies of neural structure
- DNA data collection at NSA meetings
- Examination of environmental interactions with genetic/neurophysiologic factors
- Infusion of young investigators and clinicians

- Support for doctoral student research and to attend meetings
- Mentoring programs for undergraduate and graduate students
- Multi-disciplinary meetings
- Outreach to other professional organizations

As with the other working groups, the participants in the Brain and Behavior group identified several roadblocks to research, such as the expense involved in studies of brain functioning and the accessibility of technology suitable to that purpose, the difficulty in developing cross-disciplinary research teams, and the challenges associated with establishing causality in neuroimaging studies. The group's ideas about how to overcome these roadblocks were addressed in the joint working session, as described in the next section.

Combined Language/Motor Interactions and Brain & Behavior groups. After the Language / Motor Interactions and the Brain & Behavior groups combined, they considered several ways to overcome some of the roadblocks to future research in these important areas. Examples include:

- Encouraging prospective, longitudinal studies with "at-risk" families (to identify potential differences between children who will continue stutter and children whose stuttering will resolve, either with or without intervention)
- Increasing collaborations with researchers outside of the field of speech-language pathology and developing multi-disciplinary research teams
- Improving training of current and future researchers

Several of the group's suggestions specifically focused on ways consumer groups could support future research efforts. Examples include: hosting additional meetings such as the research symposium, inviting scientists from diverse disciplines to speak at NSA conferences, encouraging support group members to participate in research studies, providing a referral source for members to become involved in research studies, enhancing training of undergraduate and graduate

students by participating in university classes and workshops, supporting training of doctoral students by providing scholarships to NSA conferences, and seeking input from consumers about research needs. The group formalized these statements in terms of a series of specific *action plans* that were distributed to group members and to the leadership of the NSA.

Finally, the group discussed the benefits of increasing awareness of research among people who stutter. Just as participants highlighted the benefits of educating researchers about the needs of consumers, they also comment on the value of educating consumers about the needs of researchers. The more that people who stutter can learn about stuttering research, the more likely they are to participate in research and to actively collaborate with scientists and educators to address the needs outlined above. Thus, the group identified several benefits of increased interaction between researchers and people who stutter, and they emphasized the important role consumer groups could play in facilitating such interactions and supporting future research on stuttering.

Risk Factors / Early Intervention: The purpose of this group was to examine research needs in the area of early identification and treatment of childhood stuttering. As mentioned in the introduction, there is a significant debate in the field about whether and when clinicians should recommend treatment for children who may be showing the early signs of stuttering. Some clinicians recommend waiting until the child's stuttering has been "confirmed" by the passage of time, while others recommend initiating treatment as soon as the stuttering is identified. Those in favor of waiting before initiating treatment highlight the significant "natural" recovery rates for preschool children who stutter, while those in favor of early intervention argue that: (a) treatment does no harm, (b) treatment may actually speed recovery, (c) treatment may help children and parents feel better about the child's stuttering during the recovery process, and (d) treatment may prevent the child from developing negative speech attitudes characteristic of more advanced stuttering.

A significant amount of research on early childhood stuttering is required to shed light

on this debate. Key research questions identified by this group included:

- What etiological factors contribute to the development of stuttering?
- What is the developmental course of stuttering, and are there different developmental tracks that can be identified that may help clinicians predict the course of a child's stuttering?
- What predictor variables should be considered when attempting to determine whether a child is at risk for stuttering?
- What are the optimal service delivery models for young children who stutter and which treatment programs represent the best course of action for different children?

The discussion group identified a number of research efforts that are currently underway to address these questions. These include longitudinal studies of the development of stuttering, long-term outcomes studies of children participating in various treatment programs, and evaluations of the cognitive and linguistic abilities of children who stutter. Group participants applauded the ongoing research, and pointed out that several studies are being conducted on a large scale, by productive, well-respected researchers. They also noted that these studies are attempting to examine stuttering close to the initial onset of disfluencies. Still, they identified a number of philosophical and methodological concerns with some of the ongoing studies. Furthermore, the group identified a number of areas where additional research is necessary, including:

- Longitudinal studies on the outcomes of a variety of intervention approaches, including consideration of the appropriate means for evaluating the value of early intervention
- Evaluation of both laboratory and field data for matching treatment programs to a particular child's needs
- Exploration of temperamental sensitivity as a possible contributing factor in the onset and development of childhood stuttering
- Coordination within the field about current areas of notable disagreement, including:

terminology, goals of treatment, definitions of success, value of frequency counts as indicators of treatment outcome, definition of functional goals for treatment, etc.

- Further discussion of the meaning of “recovery” (whether with or without formal intervention)
- Assessment of the needs of different families in treatment, in terms of treatment goals, procedures, and outcomes.

Although these and other themes resonated strongly among the participants of the early intervention group, a number of roadblocks were identified that have hampered prior research in this area. These included a perceived lack of willingness among treatment programs to make data available for analysis by independent researchers, difficulties in using current neuroimaging technology for evaluating possible etiological bases for childhood stuttering, philosophical differences and biases among researchers regarding the nature of the disorder, apparent resistance to novel methodological approaches such as qualitative research, and, notably, difficulty recruiting research subjects and lack of collaboration among research centers conducting these studies. Working group participants concluded that solutions to these roadblocks would only come through increased interaction among research centers, for conducting studies, pooling subjects, and, importantly, for analyzing new treatment data. They also highlighted the benefits of attracting researchers from other related areas to broaden the scope of study in fluency disorders.

The risk factors / early intervention group concluded its discussion by highlighting the role that support organizations such as the NSA can play in supporting the future of research in this area. They emphasized the role that consumers can play in voicing concerns about the status of early intervention research and advocating for more open reporting among programs that have not provided sufficient access to their data. They also highlighted the value of meetings such as the research symposium that allow researchers to learn more about the concerns of people who stutter and their families as a guide for future research efforts.

Research Studies Resulting from the Research Symposium

In addition to identifying research priorities, highlighting needed studies, and affirming the valuable role of consumers in the future of stuttering research, participants in several of the working groups initiated discussions about specific studies they intended to pursue following the symposium.

In the treatment outcomes groups, participants emphasized the need for clinicians to measure the changes their clients experience that may result from therapy. During the course of these discussions, a clinician in charge of a major treatment program that focuses on reducing the negative impact of stuttering on speakers' lives began discussions with researchers who are developing a new measure of treatment outcomes that focuses specifically on the negative impact of stuttering. The new collaboration has resulted in the use of the experimental measure within the treatment program as a way of documenting the overall outcomes of intervention.

In the early intervention group, one of the issues that was discussed was whether temperamental sensitivity may be a contributing factor in the onset and development of childhood stuttering. Drawing upon preliminary research studies and the experience of both clinicians and people who stutter, group members hypothesized about the nature of this temperamental sensitivity and specified a number of ways in which this sensitivity might be evaluated. The discussion resulted in a new collaboration among researchers, clinicians, and people who stutter aimed at testing several novel hypotheses about the role of temperament in the development of stuttering.

In the attitudes group, participants discussed the importance of studying the specific factors that influence public perceptions about stuttering. A subgroup of the participants outlined a study designed to examine one of the key variables: self-disclosure of stuttering. Specific research questions to be asked include: How does self-disclosure impact attitudes towards a person who stutters? Does the time of disclosure (beginning of the interaction or after a moment of stuttering) have an effect on the

attitudes people have of a person who stutters? Following the conclusion of the symposium, several participants in the working group have expanded this collaboration and developed further plans for studying the factors that influence public opinion about stuttering.

Finally, several participants at the meeting had recently initiated plans for a study to examine the potential benefits of medication and cognitive-based therapy for adults who stutter. These researchers were able to use the research symposium as an opportunity to meet and exchange ideas about their upcoming study. Although the plans for the study were not directly initiated at the research symposium, the opportunity for scientists to meet and expand their interactions was one of the key goals of the symposium.

Together, these partnerships demonstrate some of the tangible ways the symposium supported current and future research on stuttering, underscoring the success of the meeting.

Preliminary Evaluation

The final plenary session of the symposium was devoted to a preliminary evaluation of the meeting, conducted in the format of a guided discussion. Participants were given the opportunity to comment on several aspects of the meeting such as the general format of the symposium and whether or not the meeting achieved its stated goals. Opinions were expressed by many individuals representing all of the key constituencies at the meeting: research, clinical and consumer. The immediate feedback was a valuable tool not only for evaluating this first joint symposium on stuttering research but also for determining whether future symposia should be considered.

Logistics and format. There was general agreement that holding the symposium in conjunction with the annual NSA Conference was beneficial. Participants emphasized the value of providing an opportunity for researchers to meet and interact with people who stutter from a variety of backgrounds and locations. For some scientists, it was the largest group of people who stutter they had ever encountered. Interactions during the meeting and in infor-

mal gatherings were judged to be invaluable for both research and clinicians. Similar positive comments were made by consumers.

Some participants expressed concern that the meeting was unavoidably scheduled at the same time as another major meeting on stuttering, which was in Oxford, England. Because of the scheduling conflict, several influential scientists were unable to attend. It was also noted that some of the working groups were not equally balanced in terms of the number of consumers, scientists, and clinicians participating in the discussions. Admittedly, this is always a potential result for meetings with an open format where participants can self-select their working groups, and the participants agreed that the ability to self-select topics and groups was better than assigning participants to groups that may have been outside their areas of interest. Understandably, those groups dealing with the issue of treatment outcomes were more heavily attended by consumers than groups dealing with basic research; however, it was noted that at least one consumer participated in each of the working groups.

Of critical importance was the opportunity for participants to break down barriers between the professional and consumer communities. It was apparent that consumers gained a new appreciation for the fact that the investigators engaged in stuttering research really do care about people who stutter—their interest is not purely clinical or scientific. Also, researchers expressed their appreciation to people who stutter for their active participation and positive input during the symposium.

The open format of the meeting was also regarded as a unique and innovative design. Several participants took advantage of the freedom to move between different groups so they could discuss topics of direct interest to them. As noted above, two groups that had initially met separately decided to merge because of a significant overlap in their topics. All commented that the frequent plenary sessions were helpful so participants could learn more about what other groups were discussing. Hearing about other groups helped to maintain continuity between and among groups. It also enhanced the discussions within

each group. The only criticism offered during the evaluation session was that there was not enough time allotted for the plenary sessions.

Achievement of Goals. The primary aims of the symposium were to identify research needs in various areas of stuttering, develop approaches for addressing those needs, and facilitate collaboration between and among researchers and consumers. During the evaluation session, participants provided input about accomplishments in each of these three areas.

To identify research needs. All groups discussed research needs in detail. While many specific needs were identified, some participants expressed disappointment that certain areas in the discipline were not represented. It appeared that the reason for this was the fact that discussion topics tended to follow the research interests of those in attendance, while research areas that were not discussed tended to be those studied by individuals who were unable to attend. Nevertheless, those at the meeting felt that the informal group discussion format provided the opportunity to discuss what was known about current research and to brainstorm about current and future needs. An interesting outcome of the discussions was the fact that few of the scientists and clinicians knew about research projects being conducted by other scientists and clinicians, and the symposium provided an opportunity for investigators to exchange information and share opinions about each other's studies.

To develop approaches for addressing research needs. Much of the time in the working groups was spent discussing ways to solve current and future research needs. Each group developed its own "personality" and method for addressing these issues. There was agreement that the informal format allowed for open and generally congenial exchange of ideas. Some participants commented that, while the symposium was an interesting and enjoyable exercise, they were not optimistic about the future of stuttering research given the current lack of resources supporting research on the disorder. Others were more optimistic, stating that the spirit of the meeting itself would lead to future advances. In general, all participants highlighted the importance of consumer groups in the future of stuttering research.

To facilitate collaboration between researchers and consumers. In each of the working groups, there was extensive discussion about the role of the consumer in future research on stuttering. There was unanimous agreement that the joint symposium was a positive and historic event. Participants identified several ways consumers and consumer organizations could play a helpful role in stuttering research. Being strong advocates for research was seen as critical. With many training and research programs moving away from fluency disorders, it was suggested that strong consumer advocacy may be necessary to support the future of the field.

In addition, several comments were made about the importance of providing people who stutter with information about ongoing or proposed research. Appreciation was expressed to the NSA for the establishment of a research committee to monitor and promote research and to assist in locating subjects for research. Hope for continuation and expansion of the program was expressed.

Finally, participants discussed the importance of financial support for future research. Suggestions were made about ways the NSA could work toward becoming a funding source that might support specific research projects or provide grants to doctoral students in communication disorders. It was very apparent from this discussion that there is an increasing desire for consumers and researchers to work more closely together in the future.

To facilitate collaboration among researchers. There was consensus that coming together for the symposium was conducive to the collaborative process. In fact, as noted above, at least three *new* projects were discussed and formalized during the meeting. In this respect, the meeting accomplished one of its most important goals. Another of the key goals was to bring consumers and researchers together to break down old perceptions and build new bridges. An unexpected positive outcome was the new professional and personal relationships forged between scientists. Specific factors that contributed to this positive outcome were the small size of the meeting and the informal nature of the interactions. Also of great importance was the fact that the symposium

was hosted by the NSA and was therefore not perceived as a pure “research” meeting. This allowed participants to approach their discussions from an exploratory perspective, rather than feeling the need to prepare formal presentations of their research ideas.

Summary and Future Directions

This first joint symposium for researchers and consumers attracted a wide range of participants from both the professional community and the community of people who stutter. Participants addressed a variety of topics in the field of fluency disorders and highlighted key needs for further research on stuttering. Participants gained the opportunity to interact with others who shared common interests and similar experiences. New and existing research projects were discussed, partnerships were initiated, collaborations were enhanced, and the participants looked toward the future. The comment most frequently heard in the halls was “when can we do this again?” Thus, the symposium achieved its most important goal: to bring people together who share a common interest in further research on stuttering.

Clearly, this first symposium was a success, though there is still much to do. This meeting demonstrated that it is possible for a consumer organization to play a major role in the future of stuttering research. As the NSA Research Committee and the Board of Directors look toward the future, they see a continuing need for additional meetings that bring researchers, clinicians, and consumers together to discuss research on stuttering. Future meetings will include participants from other scientific disciplines (e.g., psychology, psychiatry, medicine, physiology, and sociology), as well as greater participation by people who stutter and their families (most notably, parents of children who stutter).

The National Stuttering Association will continue to expand its efforts to support research on fluency disorders, through the efforts of the Research Committee and through future conferences aimed at facilitating interactions among individuals interested in stuttering research. Together, we can all work to “brighten the future for people who stutter.”

Acknowledgements

Pioneering Stuttering Research in the 21st Century: The First Joint Symposium for Scientists and Consumers was first conceived at the 2000 Convention of the Canadian Association for People Who Stutter (CAPS) in Toronto, Canada during discussions between NSA Chairman Lee Reeves, NSA Executive Director Annie Bradberry, and researcher Luc DeNil. Together, they reflected on the fact that it would be mutually beneficial for consumers and researchers to learn more about each other, that is, for people who stutter to learn more about current research and for scientists to learn more about the thoughts and concerns of people who stutter. They presented the idea for a “joint symposium” to the NSA Board of Directors, who agreed the NSA would be an ideal organization to host such an event.

Naturally, an undertaking of this magnitude required the efforts of many people. The symposium steering committee, consisting of J. Scott Yaruss, Lee Reeves, Luc DeNil, Larry Molt, Tony Caruso, Jim McClure, Gerald Maguire, Ken St. Louis, and Bob Quesal, devoted many hours to the development of the format, list of potential attendees, and selection of general topics. The administrative expertise of Annie Bradberry and Tammy Flores of the NSA national office allowed the event to run smoothly and efficiently. A very special word of thanks is extended to Charlie Diggs, Director of ASHA’s Consumer Affairs Division, for his continued support of consumer programs, and to Eli Lilly and Company for an Educational Grant that was instrumental in making this historical meeting possible.

The steering committee is particularly grateful for the effort of the group leaders (Walt Manning and Alex Johnson, Nan Bernstein Ratner and Kevin Eldridge, Steve Hood and Joe Donaher, Ken St. Louis and Gary Rentschler, Larry Molt and Ben Watson, J. Scott Yaruss and Bob Quesal), and all of the participants at this historic meeting. Lastly, appreciation is extended to all of the scientists, clinicians, and consumers who were unable to attend but who offered their support and encouragement for what we hope will be the first of many joint meetings focusing on the future of research in stuttering.

This summary report was prepared by J. Scott Yaruss and Lee Reeves, with considerable input and help from Bob Quesal. Rod Gabel and Gary Rentschler provided helpful reviews of the final version of the manuscript.

Appendix A: Roster of Participants**Jenna Batik**

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University of Maryland

Annie Bradberry

National Stuttering Association

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Tim Bryant

National Stuttering Association

Eugene B Cooper

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European League of Stuttering Associations

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E Charles Healey

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Larry Molt, PhD

James A. McClure

Ken St. Louis, PhD

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Paul Bittorf

Tim Bryant

Ernie Canadeo

Steve Fogarty

Randy Hoover

Barry Liben

James A. McClure

Bill Parry

Ed Weiss

J. Scott Yaruss

Appendix B: Symposium Agenda*Tuesday, June 25, 2002*

7:00 – 9:00 p.m.: Evening reception for participants

Wednesday, June 26, 2002

8:00 – 9:00 a.m.: Welcome and opening remarks

Lee Reeves (NSA Board Chairperson)

Scott Yaruss (NSA Research Committee Chairperson)

9:00 – 11:00 a.m.: Working group discussions

What are the key research questions in this area?

What is currently being done to address these questions?

What are the needs for additional research to address these questions?

11:00 a.m. – 12:00 noon: Plenary session (all participants)

Sharing of results of discussion from the first working group sessions

12:00 – 1:30 p.m.: Working lunch

1:30 – 4:00 p.m.: Working group discussions (continued)

How can the identified current and future needs for research in this area be met?

What are the roadblocks to meeting these needs?

What collaborative and other strategies can be developed to overcome these roadblocks?

4:00 – 5:00 p.m.: Plenary session (all participants)

Sharing of results of discussion from the second working group sessions

Thursday, June 27, 2002

8:30 – 9:00 a.m.: Brief remarks and additional charges to working groups

9:00 – 11:00 a.m.: Working group discussions

What action plans based on new and existing models of funding and collaboration can be developed to generate needed research in this area?

What roles can consumer organizations play in these efforts?

11:00 a.m. – 12:15 p.m.: Plenary session (all participants)

Sharing of action plans and suggestions for collaboration from working group sessions

12:00 – 1:00 p.m.: Closing remarks / Evaluation



**Pioneering Stuttering Research in the 21st Century:
The First Joint Symposium for Scientists and Consumers**

Summary Report and Proceedings

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