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| **Project Title** | Voices of people who stutter/clutter (Teaching with FluencyBank) | |
| **Purpose of the Study** | *This research is being conducted by* ***Professor Nan Bernstein Ratner*** *at the University of Maryland, College Park, with the endorsement of the International Cluttering Association (ICA). We are inviting you to participate in this research project because you are an adult who stutters or has a fluency disorder. The overarching goal of our research is to identify the behavioral, cognitive and affective features that distinguish fluency disorders such as cluttering or stuttering and more typical disfluency seen in first and second language learners. The purpose of this research project is to document behavioral, affective and cognitive components of fluency disorder in adults. These videos would also be accessible by university instructors in order to better prepare them to provide optimally informed and sensitive care to their clients*. | |
| **Procedures** | *The procedures involve answering a series of questions, while you are video-taped; the video and would then be posted to an Internet site at the new FluencyBank project (at Fluency.Talkbank.org). In addition, we will ask you to complete a questionnaire that the International Cluttering Association (ICA) designed to appraise the affective and cognitive consequences of living with a fluency disorder. Upon entry into this project, you will be assigned a number, which will be used to link your videotaped interview to your ICA form. If you decide to answer both the stuttering and cluttering questions, your answers will be linked at the site.*    *The ICA has written a general introduction to this project:*  *“We are thankful for the participants who volunteered their time to have their speech recorded for the purpose of showing others speech characteristics they consider associated with cluttering. The* ***International Cluttering Association*** *(ICA), through an Ad Hoc Committee, proposed the protocol that was used for recording the speech samples now available on the Fluency Bank. We also thank others--including clinicians, researchers and the Administrators of the Fluency Bank project--for their time to make the recordings available through the media link on the Fluency Bank. According to its Administrators, the Fluency Bank is envisioned as a repository of a variety of fluency samples primarily for educational purposes.”*  *Please first refer to recording instructions provided by the Administrators of this Fluency Bank. If someone is helping you make the recording this person can ask you the questions. However, if you record yourself, just print out the questions and answer them from the paper in front of you, first reading the question you are answering. Feel free to illustrate or give examples to your responses.*   1. *Do you feel like you’re often ‘on the go,’ having the urge to talk fast or to ‘spit everything out’ as quickly as possible? Please explain.* 2. *Do you feel that sometimes you don’t quite say what you mean or mean what you say? Please explain or give examples.* 3. *Do others at times find it difficult to understand your speech or follow your train of thought? If so, please explain.* 4. *If people often say ‘What?’ when you speak, why do you think people react this way?* 5. *Is your communication better in some speaking situations than others? For example, is what you say easier to understand and follow when you are more aware of what you say and how you say it?* 6. *Is your speech different when you speak in shorter sentences compared to when you have to provide a lengthy explanation of something? Please illustrate.* 7. *Do you think you have both stuttering and cluttering? If so, what aspects of your speech reflect stuttering and which aspects would reflect your cluttering?* 8. *In what ways has your cluttering affected your quality of life (either positively or negatively) along the following dimensions:*     1. *Psychosocial (impact on interactions with others, on yourself as a communicator)*    2. *Educational, professional, occupational*   *9. Did you receive a formal diagnosis of cluttering from a speech-language clinician or did you arrive at this diagnosis primarily on your own?*  *Thank you kindly for your thoughtful responses.* ***You may choose not to answer some of these questions.*** *You will be allowed to spend as much time as you like answering each or all of these questions. We will allow you to review your videotaped interview before posting and request edits or non-contribution of your interview and ICA form. At any point, you may notify FluencyBank in writing or by email* ***at any time*** *if you would like us to remove your video and/or forms from the FluencyBank site; you do not have to provide us with any reason for your request to remove your contributions.* | |
| **Potential Risks and**  **Discomforts** | *There may be some risks from participating in this research study. The primary risk is that a person who attains access to the password protected site may identify you as a person who clutters, and may identify your treatment history. If you perceive any risk or discomfort from your contribution, you have the ability to remove your data from the FluencyBank at any point.* | |
| **Potential Benefits** | *There are no direct benefits from participating in this research. However, possible benefits include better preparation of clinicians in training to work with people who stutter, clutter or who have other fluency disorders. We hope that, in the future, other people might benefit from this study through improved understanding of the complexities of fluency disorder and can use the data from FluencyBank to improve research, clinical education and advocacy for people with fluency disorders.* | |
| **Confidentiality** | *Because your contributed sample is videotaped, it is possible that a user of the Fluency Bank may recognize you, even though your name will not be posted with either your video interview or survey. Any potential loss of confidentiality will be minimized by assigning you a number. The linkage between this participant number and your consent form information will be maintained in a secure location (locked files, encrypted files) by the PI (Ratner) at the University of Maryland. Only individuals supervised by Dr. Ratner will have access to these data, for the purposes of transcription for Bank use.*  *If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.* | |
| **Compensation** | *You will NOT be compensated for your participation in this project.* | |
| **Right to Withdraw and Questions** | *Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.*  *If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report a concern related to the research, please contact the investigator:*  ***Nan Bernstein Ratner, Professor***  *Department of Hearing and Speech Sciences, 0100 Lefrak Hall*  *University of Maryland,*  *College Park, MD 20742*  *301-405-4217,* [*nratner@umd.edu*](mailto:nratner@umd.edu) | |
| **Participant Rights** | *If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:*  **University of Maryland College Park**  **Institutional Review Board Office**  **1204 Marie Mount Hall**  **College Park, Maryland, 20742**  **E-mail:** [**irb@umd.edu**](mailto:irb@umd.edu)  **Telephone: 301-405-0678**  *This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.* | |
| **Statement of Consent** | *Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.* | |
| **Signature and Date** | **NAME OF PARTICIPANT**  **[Please Print]** |  |
| **SIGNATURE OF PARTICIPANT** |  |
| **DATE** |  |