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SPECIAL INTEREST DIVISION 4

Fluency and Fluency Disorders

The following article, by then-Coordinator of Special Interest Division 4, Fluency Nan E. Bernstein Ratner, appeared in the August 2001 issue (Vol. 11, No. 3, pp. 1-4) of the Division 4 member newsletter. It is reprinted online by permission from the publisher, the American Speech-Language-Hearing Association.

For more information on the topic, ASHA members can access online a copy of "Data and Ethics: The Tudor Study," by Ehud Yairi, published in May 2002 in the American Journal of Speech-Language Pathology (www.asha.org/members/deskref-journals/journals/ajslp/11/02/ajs11020190).

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Nan E. Bernstein Ratner

Coordinator's Corner

Rumour is a pipe
Blown by surmises, jealousies, conjectures,
And of so easy and so plain a stop
That the blunt Monster with uncounted heads,
The still discordant wavering multitude,
Can play upon it.

King Henry IV, Part II

Are there monsters in our past? In our present? Recently, the print and electronic media, including prominent national outlets, publicized an old study with provocative implications for ethical conduct in research and our beliefs about the underlying nature of stuttering. For the benefit of those who have not seen this coverage, I will briefly recap the story. In 1939, Mary Tudor, a master's level student of Wendell Johnson's, conducted a thesis designed to investigate the effects that labeling a child as a stutterer would have on his or her fluency. The intent of the study was to test what has come to be called the diagnosogenic theory of stuttering. Indeed, the study's title specifies its intent: *An experimental study of the effect of evaluative labeling on speech fluency*.

By today's standards, the study design was completely unethical. Johnson and Mary Tudor selected four groups of Iowa orphans to test her thesis, including a group of supposedly normally fluent children whose treatment protocol was designed to induce stuttering.

In the flurry of media coverage, two messages became inextricably mixed, leading to confusion on the part of those who stutter and their families, as well as some clinicians not familiar with current research and treatment in stuttering.

One message was that a study in our field had violated contemporary standards of human subjects protection. We are probably familiar with ethical travesties in other disciplines; for speech-language pathologists, this revelation may have been a first hint that our profession, too, has had its darker moments. Reading the thesis, available to the public, does little to reassure a modern reader: Mary Tudor had a hypothesis that environmental feedback could cause a normally speaking child to stutter, and she, her advisor (Johnson), and those who signed off on her thesis appeared to have had little concern about the ramifications should her hypothesis be upheld. By today's standards, such an experiment is unthinkable and raises the specter of other tragic studies of its era: seeing the effects of untreated syphilis on African-Ameri-

can men in Tuskegee, exploring the “ice-pick” method of lobotomy on the mentally ill. None would pass the muster of human subjects protection today, and so we read of such experiments with sadness and revulsion, and with appreciation of how far science has come in achieving its important ends without individual human sacrifice.

However, the second message conveyed by the news media was equally important, but more crucially, wrong. This message was that Mary Tudor had in fact proved that adult feedback to a normally fluent child could induce stuttering. This conclusion is terribly false, both by the data in the thesis itself, and the 60 years of research since the thesis was written.

I have in my possession a copy of the original thesis. Examination of the study data show a number of problems that would prevent the thesis from acceptance today, let alone publication, even if its ethical problems did not exist. Mary Tudor and Wendell Johnson had a real desire to show the effects of diagnosis, or labeling, on a child’s fluency. However, the pre-intervention data, the nature of the intervention, and the post-intervention data lead me to believe that the experiment did not induce stuttering, and that the type of treatment the children received in no way duplicates even the least helpful environment a child might encounter during development. Below I will explain my position, and then I hope you will explain it to the many parents who have already come to our clinic holding the news clippings, concerned that they are at fault for causing their child to stutter.

Johnson and Mary Tudor had five judges listen to the children she selected for this intervention before and after her instructions to them. She additionally took her own measurements of their speech during story telling. Often her data (those reported by the *Mercury News*) and that of her judges (not reported by the *News*) do not agree: for example, the pre-intervention fluency ratings of the children she considered normally fluent did not differ appreciably from those she placed into the stuttering groups. But on one thing, she and her judges would eventually concur: She herself never concluded (much to her apparent disappointment) that she had caused the children to stutter. This was despite the fact that her “intervention” went far beyond labeling six normally fluent 5-15 year old children as stutterers. Specifically, her instructions and messages to these children, whose fluency pre-intervention, included the following:

- You are beginning to stutter.
- Your stuttering is undesirable.

(She then followed this notice by threatening that the children in the orphanage with the most severe

stuttering symptoms had begun by demonstrating the very same symptoms she noted in their speech.)

She then provided advice, advice that went far beyond mere labeling of the stuttering, and encouraged the child to react to his or her disfluencies:

Thus, you must remember:

- Not to speak unless you can speak fluently.
- Avoid stuttering at all costs.
- Take a deep breath to avoid stuttering.
- If you stutter, you must stop and repeat what you said.
- Press your lips tightly together to avoid stuttering.
- Press your tongue against the roof of your mouth to avoid stuttering.

Each of these messages was administered at a virtually 100% rate of reinforcement contingent upon any normal disfluencies, through approximately eight visits per child, although the study was not framed as an operant intervention. It is important to note that most of this advice would greatly aggravate true stuttering. Though she had enlisted adults in the institution to follow the children with her advice and feedback program, Ms. Tudor was upset that only she seemed to be motivated enough to follow this schedule, and attributed her failure to uphold her hypothesis to the lack of cooperation of the institutional matrons (“... if the writer had had more cooperation, the results of this study would have been more positive [sic] ... the suggestions were for the most part disregarded.”) Today, one may entertain notions that the lack of personnel support was due to common sense or compassion.

I digress for a moment to consider that if someone were to substitute the terms “walking” or “breathing” for “disfluency,” we would not be surprised to find that children changed behavior following such harassment, and so they did. What is important to note is that the children **did not** begin to stutter. We know this from Mary Tudor’s own fluency counts, rather than her occasional observations culled for the *News* story, and from the appraisals of the five judges she used to verify the study outcomes. While disfluencies rose in the group of children “punished” for their disfluencies, the rise was in behaviors **not** typically associated with stuttering, such as pausing and interjections. These behaviors are very normal disfluencies, and no speech-language pathologist today would confuse them with clinical stuttering. Even Mary Tudor, in summarizing her findings, made the following notes:

All of the subjects ... showed similar types of speech behavior... A decrease in verbal output was characteristic of all six subjects; that is, they were reluctant to speak and spoke only when they were urged to. Second, their rate of speaking was decreased. They spoke more slowly and with greater exactness. They had a tendency to weigh each word before they said it. Third, the length of response was shortened. ... Fourth, they all became more self-conscious. They appeared shy and embarrassed in many situations. Fifth, they accepted the fact that there was something definitely wrong with their speech. Six, every subject reacted to his speech interruptions in the same manner. Some hung their heads, others gasped and covered their mouths with their hands; others laughed with embarrassment. (p.148)

The judges concurred. **Not one** viewed the post-intervention samples as characteristic of stuttering, writing “non-stuttering” over and over again in the notes, although, interestingly enough, a number of children who did not stutter before the study, and who were assigned to “control” conditions in which their speech was **not** punished **were** later labeled as stuttering at outcome, rather than at intake. In fact, the judges’ mean fluency ratings of the four groups of children, two of which were stuttering before the study began, and two of which weren’t, including the one exposed to the treatment we are discussing, were indistinguishable: 2.9, 2.8, 2.9 and 2.9 out of a possible five points. What they did agree, in consensus with Mary Tudor’s observations, is that the children developed what we might now call *communication apprehension* about their speech. They were embarrassed to talk, adopted strange mannerisms to avoid stuttering, spoke little, avoided eye contact, and were visibly loathe to talk to strangers or in front of groups. Two were, rather pitifully, referred to by one judge as “browbeaten” following intervention.

This is a real outcome, and we must not, cannot, and should not dismiss it. It was a horrific outcome with real consequences to some of the unwitting child participants. However, to call it stuttering is misleading. To call the study evidence that labeling early stuttering can cause it to persevere or worsen is even **more** misleading and potentially a greater tragedy to larger numbers of today’s children. Social phobia about speaking is not stuttering, although it mimics some of its symptoms. To induce it through extraordinary punishment of children one cannot imagine in any household today is no more informative of the cause of stuttering or its chronicity than a number of analogous experiments. Trivially, I can give you a headache if I

hit you with a hammer, but most purchasers of aspirin didn’t get their headaches that way. More to the scientific point, the child language acquisition researchers have long ago conceded that one can teach an ape bits and pieces of language, but two important facts remain: it won’t happen normally, it takes extraordinary and unnatural measures, and the result looks a little like human child language, but it isn’t. This is the real message of the Monster study: You can produce bits and pieces of what we recognize as part of an individual’s experience with stuttering if you try hard enough to violate every bit of common sense and compassion in childrearing, but since that’s not the way things really happen, what exactly have we learned?

I do not believe that parents will avoid bringing their stuttering child for early intervention because they fear we engage in unethical practices. They do not see us as monsters. But the rumor, as Shakespeare notes, is that if they bring a child to us, they have labeled a child and therefore condemned them to disfluency. This is the true tragedy of the recent coverage. By telling parents that adults can cause stuttering by their responses to a child, they have literally turned the scientific clocks back 60 years, back before so many of us pledged our research careers to absolving them of the guilt we felt that they had never earned. We know, given our work, that the diagnosogenic theory, Mary Tudor’s extraordinary experiment notwithstanding, is wrong. Her advisor, Wendell Johnson, himself contributed a tremendous amount of positive information about stuttering and its effective treatment that weakened the strength of the diagnosogenic hypothesis. More recently, genetic studies, environmental studies, and counseling, behavioral and operant treatments that actually acknowledge stuttering and fluency in young children in a compassionate manner, such as a number of very successful therapies for young children currently do, are all completely inconsistent with the notion that attention to a child’s fluency, if framed carefully, will create or maintain a fluency disorder. In fact, as many of us have found, acknowledgment is an important aid in helping the child to avoid development of secondary behaviors stemming from fear, anxiety, shame, and guilt about stuttering that emerges when stuttering cannot be discussed in a household.

In summary, there are a number of take-home messages from the media coverage of the “Monster Study,” but I would argue that they are different than those intended by the media coverage. The real messages are that:

1. This study did **not** show that drawing attention to speech causes stuttering. (In fact, one of my students noted that, given the intensity of negative feedback the children received and the fact that

they did not begin to stutter, the thesis may stand as the best argument **against** the diagnosogenic theory);

2. Talking about stuttering does not cause stuttering;
3. Parents should not believe media coverage of controversial experiments that do not include evaluation of the studies' findings by recognized experts in the field; and, obviously,
4. This kind of research was not ethical and would never take place in today's world.

The fourth message seems to have overwhelmed the other three, which are much more important, because the dangers they represent exist in the present, rather than the past.

What then are the consequences of the recent media flurry? Beyond the opening of old wounds, parents who will not bring their young children to specialists when they first begin to stutter for fear of creating a chronic disorder prevent us from understanding the root causes of stuttering. In this sense, Johnson and Mary Tudor's work was truly monstrous, although not as monstrous as the unthinking press releases that are rehashing her study: 60 years later, parents can again feel grief, guilt, and doubt, while they and their children become too frightened to seek the help, counseling, and intervention that we know can help them. If you agree, please help parents and your local media understand the terrible injustice that can come from waking long dead monstrous rumors.
