

# The Value of Collaboration in Advancing Science in Cluttering

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## 1. Introduction

This paper reflects the views of a cluttering researcher-clinician and an advocate of those who clutter who has spoken and written extensively about his experiences with cluttering. The paper is a reflection on the value of collaboration in advancing science in the field of cluttering. The outcomes of collaboration among researchers, clinicians, and people with cluttering are explored, and the benefits and future direction of collaboration in the area of cluttering are discussed. In the sections that follow, each of us, in turn, provides our first-person perspective on the value of collaboration in research on cluttering.

## 2. The Required Shift in Thinking: Perspective of a Researcher and Clinician

As a new doctoral student in 2005, I realized how little information was available about cluttering. I also realized that, in comparison, the field of stuttering advanced in significant ways when we as researchers and clinicians began actively listening to the insights of the true experts: those who stutter. Trying to follow in those footsteps of stuttering, researchers, myself included, began to talk with adults who clutter and parents of children who clutter. Through this process, we were able to compile more information to clarify common misunderstandings about cluttering. Learning from the voices of those who experience cluttering themselves or those who experience it as communication partners, we now understand that even in the absence of diagnosis or one's awareness of cluttering in their speech, those who clutter can experience negative life impacts (socially, educationally, occupationally) from living with cluttering. Our collaboration also allows us to continue to gain insight about rate of speech, potential language components of cluttering (do they exist or not?), and concomitant stuttering (is it less common than we originally thought?). All of these areas are far from settled and require further exploration and study. Exploring the answers to these questions means more than designing empirical studies from a researcher's perspective alone. Rather, we need to continue to move away from researching *about* people who clutter and toward researching cluttering *along with* individuals who clutter. The field of stuttering has already made a similar shift, with several teams of researchers exploring stuttering in collaboration with those who stutter (e.g., Douglass et al., 2019; Gerlach-Houck et al., 2022; Yaruss, Quesal, & Murphy, 2002). Though ethnographic interviews, focus groups, and simply listening to clients' stories offer excellent opportunities for learning, collaboration with people who clutter offers an even richer opportunity to discover the most critical questions that may lead to a fuller understanding of the experience of cluttering. In particular, through our collaboration, those who clutter can speak to what questions are most important to answer and provide the insight clinical researchers need for going about answering them. I am not suggesting picking the brains of those who clutter and moving on without them. I am suggesting working side by side, in partnership, to create studies that can ultimately educate clinicians and the public. Such work has the potential to provide more socially valid research conclusions, as the work doesn't simply *consider* perspectives; it *integrates* the perspectives of individuals living with cluttering.

## 3. Outcomes of Collaboration: Perspective of a Person Who Clutters

As a person who clutters originally misdiagnosed with only stuttering, I have learned a great deal in my conversations and collaborations with people who clutter, clinicians, and researchers. I have learned about unique differences that distinguish stuttering from cluttering. I have learned that although each person's experience with cluttering may be unique, some people who clutter share commonalities, such as awareness of negative listener reactions and negative life impacts, including when cluttering overshadows the speaker's other capabilities. Through talking with people with cluttering I have found that many feel alone in their search for answers. Through collaborations with clinicians I have learned just how little education they receive on the topic of cluttering. In response to these challenges I have partnered with expert clinicians on presentations and shared my experiences. Writing about my experiences (Wilhelm, 2020), as well as sharing them through my website ([toofastforwords.com](http://toofastforwords.com)), has also led to collaboration with researchers in the field of cluttering. On my website, the views of clinicians,

researchers, and people who clutter are freely represented, so that all can continue to learn from each other. My hope is that our continued collaboration through presentations, research, and writing projects can continue to improve existing resources for people who clutter.

#### **4. Our Direct Research Partnership**

We recently partnered on an article that described a series of structured conversations with community leaders with cluttering. Rutger, second author, participated as a leader along with Joseph Dewey, a person with cluttering who has developed online support and educational resources about cluttering, and Sister Carol Mary Nolan, founder of the Cluttering Facebook group. Because all of these individuals had their own experiences with cluttering to share and because they have all interacted in different forums with many individuals with cluttering and those who care about them, they seemed like the perfect three to share their views on the perspectives of those who clutter. The first author and her graduate student presented these leaders with recommendations or viewpoints often represented in stuttering, and asked their perspective on how these viewpoints differed for clutterers. Among other topics, we discussed strategy use vs. spontaneous speaking, listener recommendations, and recommendations for caregivers. From speaking with these leaders, we gained appreciation for the notion that many people with cluttering tend to focus not on strategies per se, but on being understood by others. At times, this means regulating speech rate or emphasizing sounds. At other times, when speaking with listeners who know them well, this may mean less monitoring, due to confidence that they will be heard and understood by these listeners.

Through conversations with these leaders, we also focused on the importance of interactive listening, which involves actively listening, gently stopping the speaker when they are not following, and helping the person who clutters get back on track (if needed) after a point is clarified. This concept of interactive listening is important information for parents of children who clutter, because it provides a way to support their children that avoids frustration and misunderstanding. In addition, the leaders emphasized that some people with cluttering need help getting back on track. Hearing this message has the potential to help us focus research efforts on the exploration of working memory difficulties in cluttering. The publication that resulted from this work was Meza & Scaler Scott (2022).

So what is the takeaway for researchers and clinicians wishing to partner with those who clutter? The partnerships we discuss occurred because the first author reached out to the leaders, including the second author, for their viewpoints. Researchers should be aware that there are many who clutter willing to provide their input; they simply need to be asked. In each connection with people with cluttering, the first author finds that there are many willing to participate in the research process. Some want to provide input on design and topic, others want to contribute their voice. In terms of clinical partnership, the second author has provided many educational workshops for SLPs to better understand cluttering. A first step for clinicians and researchers in partnering with those who clutter is to connect with them through media such as the Cluttering Facebook group. Ask questions, listen to perspectives, and let the wants and needs expressed by those who clutter guide you from there. For those who clutter who would like their voices represented and/or to participate in all stages of the research process, please don't hesitate to reach out to us or to others within the cluttering community with your wishes for participation and your perspectives.

#### **5. Continued Challenges and Needs for the Future**

Despite our advances, daily we are faced with the need to educate others. Both of us have encountered misinformation about cluttering among SLPs and other professionals. For example, we have encountered professionals who suggested that people with cluttering couldn't hold certain jobs. We've heard of others seeking help who were dismissed by SLPs without diagnosis, for reasons such as the SLP linking rapid rate to regional speech rather than a true communication disorder. This kind of misinformation can be corrected by a greater understanding of the subtle issues in cluttering, such as knowing to ask during evaluation if cluttering results in the speaker having to compensate to perform well at their job. Such education of professionals could help avoid under-diagnosis or misdiagnosis by the SLP. Anecdotes of misinformation in 2022 inspire our continued collaborative efforts toward education, research, and advocacy in the name of improving the lives of individuals who clutter.

There is an ongoing need to evolve as a sub-discipline, prioritizing the provision of information and resources to people who clutter, their significant others, and clinicians. Innovative means of outreach, such as podcasts, websites, and YouTube channels, have been and should continue to be available. Additionally, more research partnerships with clinicians that focus on treatment effectiveness studies are needed. Finally, research partnerships across multiple labs and specialties can help overcome the challenge of obtaining larger samples of cluttering for empirical study. Finally, given that many who clutter are still unable to find the help they need, specialists in *stuttering* who

may not feel comfortable assessing and/or treating *cluttering* are implored to use their professional connections and resources to help direct clutterers to professionals with expertise in this area.

## 6. Our Collaborative Wish for the Profession

In closing, as you read this, you may be thinking, “Who doesn’t agree that collaboration is a good thing?” That is a first step. Following this step, we encourage educators to foster an interest in cluttering among students and to develop partnerships in collaborating with these students on cluttering-related research projects. This is how to ensure that cluttering no longer remains lost and unrecognized and that today’s and tomorrow’s researchers continue to work toward advancing the science in cluttering. We encourage clinicians to foster collaborative relationships with clients and their significant others. This is how we ensure that we can adequately support the needs of our clients. Most importantly, we encourage all to foster collaboration in research, education, and advocacy with those who clutter. May every conversation we have spawn a new project, outreach or educational effort.

## Disclosures

Financial: Rutger Wilhelm is the author of and receives royalties for the book *Too Fast for Words*, which is referenced within the article.

Nonfinancial: Rutger Wilhelm is owner of a website that referenced within the article.

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