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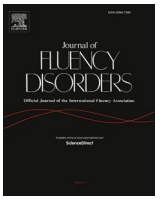

Contemporary clinical conversations about stuttering: Neurodiversity and ableism

Rosalee Shenker [a], Naomi Rodgers [b], Barry Guitar [c], Mark Onslow [d,*]

[a] Private Practice, Montreal, Canada
[b] University of Iowa, Communication Sciences and Disorders, IA, USA
[c] University of Vermont, Department of Communication Sciences and Disorders, Vermont, USA
[d] University of Technology Sydney, Australian Stuttering Research Centre, NSW, Australia

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ABSTRACT

Purpose: To discuss issues about neurodiversity and ableism, and how they pertain to clinical management of stuttering, with particular reference to early childhood stuttering.
Methods: During a webinar this year, the issue emerged of how concepts of neurodiversity and ableism apply to early childhood stuttering during the pre-school years. It became apparent that this topic elicited disparate views and would be of particular interest to students of speech-language pathology. Consequently, the leaders of that webinar continued the conversation by written dialogue for the purpose of placing it on record.
Results: The discussants reached agreement on many points, but there was some diversity of viewpoint about how neurodiversity and ableism should apply to clinical practice with children who have recently begun to stutter.

1. Prologue

The origin of this discussion was a webinar organized by Dr. Rosalee Shenker in April 2023, which featured a conversation with Drs. Barry Guitar, Naomi Rodgers, and 60 attendees. During that webinar, the concepts of neurodiversity and ableism were raised many times as the stuttering community continues to explore how these concepts apply to stuttering experiences and therapy. *Neurodiversity* is "both an empowerment movement and a way of thinking about disability" (Constantino, 2018, p. 382). Proponents of neurodiversity conceive intrinsic differences in brain development and cognitive function as natural variation in human biology rather than as pathological deficits that should be "fixed." As such, neurodiversity aligns with the social model of disability, which argues that disability is a social condition when environments are unaccommodating to people with certain traits. This contrasts with the medical model of disability which situates the "problem" with a person's underlying impairment. This directly relates to issues of *ableism,* which argues that not having physical, mental, or sensory impairments (in this case not stuttering) is better than having those differences (in this case stuttering). Ableism stems from implicit and explicit stigma about certain traits and can lead to discrimination and prejudice (Gerlach-Houck & Constantino, 2022).

Prabhat et al. (2022) draw attention to how basic research knowledge about stuttering—genomics and neuroscience—has emerged from a biological perspective. They argued that this has driven the discipline of speech-language pathology toward a medical model of

* Correspondence to: Australian Stuttering Research Centre, University of Technology Sydney, Building 1, 15 Broadway, Ultimo, NSW 2007, Australia.
E-mail address: Mark.Onslow@uts.edu.au (M. Onslow).

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stuttering, with a hope that such biological directions will eventually influence treatment methods favourably. However, the full quality of life impact of stuttering, shown recently with standard utility values, to be equivalent to cardiovascular disease and cancer (Norman et al., in press), is best understood through the World Health Organization's International Classification of Functioning, Disability and Health. This model conceives the life impact of stuttering to reflect complex and individualistic relations among the underlying impairment, participation restrictions, and activity limitations, which are necessarily impacted by personal and environmental factors (Yaruss & Quesal, 2006). The WHO-ICF model aligns with the social model of disability, focusing on how a mismatch between the person and their environment can lead to negative life impact. Further, Constantino et al. (2022) and Gerlach-Houck and Constantino (2022) argue that those who stutter live in a society that marginalises them with a range of negative stereotypes, which reflects the impact of environmental factors on experience of disability. The clinical applications of a social model of stuttering present potential challenges to approaches that prioritize behavioural changes to speech (Gerlach-Houck and Constantino (2022), an issue that is particularly important to consider for school-age children who stutter for whom fluency-focused approaches may be harmful (Gerlach-Houck et al., 2023; Reeves et al., 2023; Sisskin, 2023).

During Dr. Shenker's webinar, the issue emerged of how concepts of neurodiversity and ableism apply to early childhood stuttering during the pre-school years. That issue was raised in part because a Cochrane Systematic Review (Sjøstrand et al., 2021) concluded that the atypical behaviours of early childhood stuttering are clinically tractable. During the webinar, it became apparent that this topic elicited disparate views. Considering the clinical importance of this topic—particularly to students of speech-language pathology—the present report is a discussion among the leaders of the April 2023 seminar: Drs. Rosalee Shenker, Barry Guitar, and Naomi Rodgers, joined by Dr. Mark Onslow, who attended the webinar and suggested that the conversation was sufficiently important to continue and record. The following is a dialogue by those four authors that was conducted in a written format during June, 2023. Dr. Onslow facilitated the discussion. To ensure equitable representation, each discussant was limited to 100 words per turn.

2. Dialogue

Mark: Neurodiversity and ableism are becoming a modern movement in our field. Barry, you are on record as stating that the key to living with stuttering is to be at peace with it (Onslow, 2023). So, I am guessing that you can relate to this way of thinking?

Barry: I believe that for adolescents and adults who stutter, they should be free to choose if they want to work on stuttering in an easier, more relaxed way, or to continue to stutter however they are stuttering. For me, it is hard to imagine that I would have chosen to stutter with the struggled, tense blocks I had in my teens and early twenties if the option were presented to me to stutter in an open, smoother style. And that option was presented to me by Van Riper, and I chose it, and I'm very happy with it.

Mark: Naomi, as someone who stutters, what is your take on this?

Naomi: The recent spotlights on neurodiversity acceptance and anti-ableism seek to make communicative spaces more equitable for people who talk differently. With mounting evidence that stuttering is rooted in neurophysiology, we know that some people's brains are primed for stuttering, making it a form of neurodivergence. For those people, trying to talk in a way that is unnatural to them because of ableist notions about what is acceptable communication can heavily affect their well-being. I believe that the hard work of change should be a shared responsibility where there is both personal and societal change.

Mark: Barry gave a personal perspective, and you gave a societal perspective on this matter. Without doubt, neurodiversity acceptance and anti-ableism will ultimately benefit society, and hence, those who stutter who live in it. Also, without doubt from what you and Barry said is that some who stutter might wish to find a way to deal with it, but it would not be sensible to impose any such approach on anyone who stutters. Rosalee, you have a specialist clinic for stuttering. What are you thinking about all of this?

Rosalee: I feel that when stuttering persists past pre-school age, treatment must begin to address the combined goals of acceptance and decreased struggle, seeing stuttering as a difference rather than a disorder. If, historically, speech-language pathologists (SLPs) valued fluency as the primary treatment objective, we must not currently make the same mistakes and decide that acceptance is the therapeutic goal for all. For a clinician, some challenges will be to help the client accept the identity of stuttering, to change our training programs to reflect these goals, and to give those who stutter permission to stutter, while supporting their individualized goals, values, and choices.

Mark: Indeed, it is basic clinical common sense to assume nothing about what clients require when they come to clinics seeking help.

Barry: What's your response to this? Yesterday, I received an email from someone who works with lawyers and special education to help disadvantaged school kids get therapy. A current case [in the United States] is a fourth grader who stutters who was discontinued from stuttering therapy because the field of communication disorders now believes that it is too traumatic to teach kids who stutter to communicate more effectively. Instead, they must be taught just to tell people that they stutter. Is this neurodiversity or neuro-misunderstanding?

Mark: Gosh. Rosalee and Naomi, what do you make of that story?

Naomi: Because of the current debate about medical versus social models of stuttering, as well as recent accounts that some speech therapy approaches do harm by teaching kids nothing more than how to conceal stuttering, I understand that many SLPs are feeling wary about providing stuttering therapy. And rightfully so—no one becomes an SLP because they want to harm people. But not all therapies are created equal. Rather than rejecting stuttering therapy writ large, we should critique fluency-focused approaches, expand our collective skillset to holistically support people who stutter, and advocate for greater societal understanding and inclusion.

Mark: Rosalee, what is your response to Barry's story?

Rosalee: This was my concern: his case describes a "false dichotomy" when a situation is unfairly represented as an "either/or" scenario. An analogy here is in Quebec, where the ministry of education determined that teachers should teach reading with only a

whole language approach, instead of teaching phonics. The program failed miserably, and a combined approach was re-instated, the conclusion being that clearly both approaches are important in teaching reading. The decision taken in the case that Barry presents is a good example of this mistaken belief that acceptance of stuttering alone is sufficient in treatment.

Mark: Then it seems that the case in question is a sobering instance of a potentially useful clinical concept our field—neurodiversity acceptance and anti-ableism—going awry because it overtakes clinical common sense. The child was unable to participate in clinical management decisions. Presumably, that would be less likely to happen to an adult, who could explain clinical needs to a clinician. So now, let's consider the other end of the pertinent age range with stuttering. How should the concept of neurodiversity and anti-ableism affect management of children shortly after they begin to stutter?

Barry: Regarding Mark's question about children who have just begun to stutter, they can gain more fluent speech relatively easily, never encountering the frustration, embarrassment, and shame that often accompanies more struggled stuttering. For kids, usually age 2 and 3, working with parents to create a warm, accepting environment, enhancing the parent-child attachment, and modelling a slower, simpler style of speaking can foster more effortless, fluent speech for the child. For children at age 4 or 5, using a direct approach that teaches the child both acceptance of their speech and ways of stuttering more easily—or speaking fluently—are warranted.

Mark: Naomi and Rosalee, what are your thoughts on this?

Naomi: I agree with Barry that one goal of stuttering therapy is often to help the client talk more easily. I think we need to be mindful of contradictory messages that are unintentionally sent to families and clients. Simultaneous messages of "it's ok to stutter" and "let's change how you talk" may be confusing to clients. For young kids, we know that a majority of them will grow through stuttering on their own. So, perhaps early intervention with young stutterers isn't about pushing fluency but, rather, helping them experience that stuttering is really OK, so they can grow with stuttering without struggle.

Rosalee: Neurodevelopmental doesn't mean intractable; there is considerable evidence that early treatment eliminates or reduces stuttering. Research demonstrates significant neuroplasticity at young ages. Pre-schoolers are likely to respond to treatment that stimulates brain development toward more typical growth patterns, and stuttering is more tractable to treatment during these years. This counters the misunderstanding that neurodevelopmental means we cannot do anything about it. Treatments that do not impose an unnatural way of speaking on the child may strengthen functions that already exist, hence, are "natural". I believe this supports a pre-school child's self-confidence as a speaker and their enjoyment of communication.

Mark: So, if I am understanding the narrative correctly, Barry and Rosalee indicate that early stuttering is clinically tractable and that becoming fluent offsets the quality of life impact of stuttering. However, Barry indicates that at 4–5 years of age things become clinically different, but Rosalee does not, referring generically to "early stuttering". And Naomi seems to be more circumspect, not being drawn to the notion of early childhood stuttering being tractable. Do I have that right?

Naomi: With roughly 80% of young children growing through stuttering without intervention, we know that stuttering is transient for most. For those that persist, I agree with Rosalee that early intervention is critical because we can reap the benefits of heightened neuroplasticity in early childhood. But the focus of early intervention can differ, and for those children who are predisposed to stutter, I think that struggle and concealment behaviours, and negative thoughts and feelings about stuttering, are tractable, not the stuttering itself.

Mark: So, Naomi, I guess you are venturing that the many randomized controlled trials of early childhood stuttering intervention have got it wrong with their primary outcome of stuttering severity?

Naomi: Overt stuttering severity has questionable reliability and validity. Many people who stutter are skilled at concealing stuttering, so sometimes stuttering events are experienced by the speaker without ever being observed by the listener. Thus, when we prioritize overt stuttering severity as the primary outcome measure, we're reducing the complex stuttering experience to a fraction of stuttering events that listeners perceive. Which may be why stuttering severity doesn't reliably predict stutterers' negative life outcomes, while accruing evidence suggests that personal and societal reactions do.

Mark: Your position is clear there. So, there is a collection of randomized controlled trials, involving three different treatments, each of which use stuttering severity as a primary outcome. A Cochrane Review of that evidence (Sjøstrand et al., 2021) concluded that treatment is better than doing nothing with children younger than 6 years old, at least in terms of reported primary outcomes. So, that body of evidence needs to be taken account of in evidence-based clinical reasoning. On the other hand, some clinicians may doubt aspects of that body of evidence and may choose to disregard it. How would you advise students and junior clinicians to take account of that research in their clinical reasoning?

Naomi: I think students should understand that the most studied outcomes aren't necessarily the most meaningful outcomes. As evidence-based practitioners, we make clinical decisions by integrating research evidence with clients' values and our clinical expertise. And research evidence comes with a caveat: closely consider (a) the social validity of the intervention and (b) how change was measured. I personally wouldn't teach students that a certain intervention is better than no intervention, because that presumes (a) participants believed the intervention was sensitive to their needs and (b) trust in the outcome measure (which, in the RCTs you referred to, is stuttering frequency).

Mark: Rosalee, what is your take on this? How would you advise students and junior clinicians to take account of randomized trials of early childhood stuttering treatment in their clinical reasoning?

Rosalee: The research shows that stuttering behaviours in pre-school children are tractable. I am not aware of any evidence showing that early treatment leads to concealment and struggle in a pre-school population, nor have I seen evidence of this in my clinical practice.

Mark: Barry, what is your take on this? How would you advise students and junior clinicians to take account of randomized trials of early childhood stuttering treatment in their clinical reasoning?

Barry: Students and new clinicians need to decide if treatments favoured in randomized trials (a) fit their personal style of doing stuttering therapy, (b) fit the child's caregiver's values and priorities, and (c) can be learned and mastered via training available to them. Otherwise, these clinicians may misuse the treatments and find them ineffective, if not harmful. Moreover, I strongly advise long-term follow-up when new clinicians are trying treatments new to them or even treatments familiar to them.

Mark: Could you expand on your point *(b)*?

Barry: At least once when I described the planned treatment, that parent decided not to have the child treated by me. Several times, when treatment was in progress and the child was upset by treatment, the parents and I decided to change the treatment. This met the parents' values.

Mark: So, none of us seems to contest that evidence-based practice is "the conscientious, explicit and judicious use of current best evidence" (Sackett et al., 1996, p. 71). So now, let me go out on a limb. There is evidence associating stuttering with adverse quality of life across domains of mental health, education, and occupational attainment. Stuttering onset occurs during early childhood with atypical speech events. There is evidence that those atypical speech events can be stopped or nearly stopped during early childhood. That is the key issue here, not whether doing so is problematic in terms of neurodiversity and ableism.

Rosalee: I have not heard any persuasive argument, or seen any credible evidence, that treating pre-school children for stuttering by a competent therapist is harmful. But there is ample evidence that early direct treatment is effective in eliminating or greatly reducing the atypical speech events of early childhood stuttering. It is incumbent on the profession to have well trained, specialized SLPs. Of course, any treatment done badly can harm the client or affect self-esteem and confidence.

Naomi: To Mark's comment, I think we disagree on the key issue; the focus of therapy *does* come down to issues of ableism. To Rosalee's comment, as someone who stutters who is very active in the stuttering support community, there are plenty of people who stutter and families who share their lived experiences through books, blogs, and social media about being harmed by early therapy experiences that did nothing more than teach them to conceal stuttering from a young age. We cannot ignore or discount those narratives because the medicalization of our profession has historically precluded this type of research.

Barry: I have just become aware of a book (Holte, 2023) by the mother of a child who, apparently, was given five years of stuttering therapy that left him still stuttering severely with appalling avoidance behaviours. She interviewed 60 parents of children who received stuttering therapy. Some kids did well, but others were made more severe. Thus, our mission should be to improve the therapy, and the training of clinicians, that young children receive—especially in public schools—so that treatment helps them feel OK about themselves and their stuttering as we help them stutter more easily, or not at all.

Rosalee: There is a role for qualitative perspectives in our field, such as the book to which Barry refers, but it must rigorously adhere to accepted scientific principles. I agree with Barry that our focus is on training of SLPs to provide best clinical practice. This would combine goals of decreasing severity and increasing communicative competence and confidence without choosing between them. Historically, our field has cycled between stutter-more-fluently and speak-more-fluently treatments. Clearly, we can combine client's goals to stutter less severely and be good communicators, while confronting ableism with information that is honest, impactful, and helpful.

3. Epilogue

After the above written dialogue concluded, each author was asked to provide a 300-word summary of their perspectives about the discussion. These personal concluding remarks were not seen by the other authors until they were all submitted to Dr. Onslow, who compiled them.

Mark: None of us doubt the need to take account of neurodiversity and ableism to serve the interests of those who stutter. And none of us question the clinical common sense that adolescents and adults who stutter should be free to stutter in "an easier, more relaxed way" (to use Barry's words) if that suits their needs. And there was no disputing the lifetime quality of life impact that stuttering has. Nor was there any dispute that evidence-based clinical practice with stuttering involves domains of evidence, client needs, and clinician skill. And of course, we were all agreed that, as with all health care, incompetent clinical practice is potentially harmful.

Clearly, though, children of pre-school age cannot make an informed decision about what clinical approach is suitable for them, and parents and clinicians must make that decision. Students of speech-language pathology who are learning about clinical management of stuttering, and speech-language pathologists who wish to take account of neurodiversity and ableism in their clinical practices, need to think about that decision.

One consideration when making such a decision is that stuttering onset occurs with atypical behaviours—repetitions, prolongations, and blocks—and that clinical trials raise a reasonable prospect that they can be stopped or nearly stopped. It also seems to be a reasonable prospect that if those atypical behaviours can be stopped or nearly stopped shortly after stuttering onset, then the adverse quality of life consequences of stuttering—equivalent to cardiovascular disease and cancer (Norman et al., 2023)—might also be stopped or nearly stopped.

During our discussions Dr. Shenker raised the perils of inflexible, dichotomous clinical thinking, and such an approach could be particularly perilous here if a medical model approach to early stuttering intervention excluded concurrent application of a social model approach to early stuttering. Adequate clinical practice with pre-school children who stutter obviously requires both models. No responsible clinician would overlook the need to deal clinically with an interaction between early childhood stuttering and the society in which it occurs.

Naomi: As with most complex issues, there are no simple resolutions. We all agree that the neurodiversity and anti-ableism movements should *not* preclude clinicians from working with people who stutter because these movements are not at odds with personal change. Yes, some people who stutter have been harmed by fluency-focused therapies—anecdotal and emerging empirical

evidence show this. It's important we acknowledge that because it helps us understand why some people who stutter oppose speech therapy and SLPs, and it intensifies the need for holistic training in which clinicians learn to promote change from a neurodiversity-affirming, ableism-informed stance. This can be done by de-prioritizing fluency, de-pathologizing the language we use to talk about stuttering, guiding stutterers to make personal changes that feel right to them, and promoting greater societal inclusion of communication diversity.

I believe we all agree this is possible for therapy beyond the pre-school years, but we have differing perspectives about what it looks like near the onset of stuttering. What should be the focus of early stuttering therapy (e.g., suppression of stuttering, struggle-free stuttering)? How are outcomes measured (e.g., stuttering frequency, stuttering quality)? Who gets to be heard when deciding which treatment outcomes are important (e.g., researchers, the stuttering community)?

While these questions are important to consider when working with all people who stutter of all ages, they are uniquely thorny when we consider therapy with pre-schoolers. Just as a neurodiversity-affirming, ableism-informed approach to stuttering therapy for school-age and older would not prioritize reducing stuttering frequency, I encourage us to do the same with pre-schoolers. And there are evidence-based approaches that do just that. Such approaches wouldn't harm those who would grow through stuttering on their own anyway, and for those who are going to grow *with* stuttering, it could lay a critical foundation for developing open, comfortable communication.

Rosalee: Neurodivergence presumes a biological permanence, an intransient difference in wiring that is the essence of certain behaviours. While atypical behaviours might be the effect of neurodivergence in one individual, those same behaviours might be transient in others. To presume that all dysfluency is the result of neurodivergences neglects those who can benefit from treatment. The pre-school years provide a unique opportunity to discover, through treatment, the characteristics of those children who continue to stutter and those who do not. Although research has been unable to identify with consensus what constitutes the active components of early intervention, it is nonetheless a possibility that early intervention may be enhanced by some component of acknowledgement.

Early intervention aims to treat stuttering before it has downstream effects. Historically, SLPs use early intervention to support and develop language, speech, and fluency. The research shows that both indirect and direct treatment models may reduce or eliminate stuttering in pre-school children. However, the mechanism responsible for this change is currently unknown. One aspect of early intervention for stuttering that is shared across treatment is the essential role of the parent, which may affect positive treatment outcome (Bernstein Ratner, 2005; Hayhow, 2011). Many existing programs train parents to provide accurate verbal feedback, encouraging fluency as well as language, speech, and communication. When this is done effectively with children presenting with early stuttering, parents learn to communicate a positive attitude toward fluency rather than a negative message that stuttering is unacceptable. This is one aspect of early treatment that merits further study. The success of early intervention programs that reduce or eliminate the severity of stuttering or parental concerns are well documented, suggesting that stuttering is alterable at this age, therefore preventing the negative consequences of lifelong stuttering. Given this evidence, withholding treatment at this age does not seem like a viable option.

Finally, I conclude that *any* extreme position on the treatment of pre-school children is incorrect. Holding the position either that all stuttering must be treated and "fixed", or that all stuttering must be seen as an acceptable neurodivergent trait, ignores the vast spectrum of individual differences. Those very differences are at the root of our case formulations, which should be dynamic and updated in real-time as new information about our clients is revealed. Randomized controlled trials should not be applied broadly to all pre-schoolers, neither should the concept of neurodiversity be simplified to apply to all young children who stutter.

Barry: My concluding thoughts are as follows. Clinicians who work with stuttering should be educated to be confident and comfortable in working with those who stutter and their families. Clinicians need to understand that it is up to the individuals, and in the case of young children, their parents or guardians, to decide if they wish to change speech so that it is more fluent. Clinicians working with younger pre-school children who stutter may be most effective in improving the child's fluency by guiding parents to provide attentive listening and attentive play with their child that shows acceptance of stuttering and, if needed, to provide a model of slower but normal sounding speech. When working with older pre-school children who stutter, clinicians may use an approach in which parents are guided to set aside time each day that praises fluent speech and occasionally requests the child, in an accepting way, to try a stuttered word again. For sensitive children, a different approach may be used that, in a positive play setting, lets the child know that stuttering is OK and at the same time gives the child many positive experiences talking easily. Clinicians working with school-age children who stutter moderately or severely must make therapy fun and must help them learn that when they stutter it's not bad, but there are easy ways to stutter. And finally, clinicians working with teens and adults should be trained to use approaches that help them accept the diversity of their way of talking, and if the client desires, the clinician should provide an approach that makes talking easier.

Declaration of Competing Interest

All authors certify the absence of any conflicts of interest, including specific financial interests and relationships and affiliations relevant to the subject of this paper.

Data Availability

No data was used for the research described in the article.

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Rosalee C. Shenker is a Speech Pathologist specializing in stuttering. In this capacity, she founded the Montreal Fluency Centre, taught a graduate course at McGill University, provided clinical training and mentoring for countless speech pathologists, and is currently a partner in Stuttering Specialists Montreal. In addition to many invited presentations nationally and internationally, she has published in peer-reviewed journals and contributed chapters on stuttering to various textbooks. Her most recent work accentuates the treatment of bilingual children who stutter and the use of telepractice for assessment and treatment of stuttering.

Naomi H. Rodgers, PhD, CCC-SLP is an assistant professor at the University of Iowa. Her program of research centres on the psychosocial aspects stuttering and communication disabilities more broadly, with primary interdisciplinary foci on how people who stutter engage in the therapeutic change process and how they process social-emotional information. She teaches speech-language pathology courses in stuttering, counselling, and clinical methods. Her work is inspired by her experiences as a person who stutters, clinician, and advocate in the stuttering support community. Barry Guitar received his PhD from the University of Wisconsin in 1974. He then worked in Sydney, Australia, for 2 years as a clinical researcher in a stuttering treatment program at the University of New South Wales. Following that, he joined the University of Vermont where he was a professor of Communication Sciences and Disorders for 42 years, teaching, supervising clinical work, and conducting clinical research. He has published widely and given seminars and workshops all over the world.

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Mark Onslow is the Founding Director of the Australian Stuttering Research Centre, which has been active since 1996. During a 30-year career, he has published more than 200 papers in peer-reviewed scientific journals. His research activities include clinical trials of treatments for children and adults who stutter, the mental health of those who stutter, measurement of stuttering, and the epidemiology of stuttering. Mark is now involved in an extensive program of research to develop standalone internet treatments for adults and children who stutter.