

Appendices

Appendix A: Overview of Methodology

VoiceS Unearthed: The Impact of Early Intervention on Those Who Continue to Stutter is a non-academic collective case study initiated to help the world attain a broader view of how childhood intervention has impacted those who continue to stutter into their teens and adult years—and their families. I have added the S to Voice Unearthed to reflect the many voices who told their stories in this effort to present a broader and more accurate picture of reality. My findings convey the impact of childhood intervention in a more naturalistic way that goes beyond the clinic setting and spans years, even decades. The collective case study framework extends beyond the limitations of randomized controlled studies, which include inability to control variables, limited time spans, and the opportunity for bias in reporting results.¹

Although this is not a scientific study, nor am I an academic, the steps I took in gathering, assessing, and presenting this information are often echoed in scientific and academic qualitative research studies. This study comprises 60 interviews, with analysis of more than 3,500 lines of narrative. I share those findings along with my reflections from more than 22 years of first-hand experience, research, and conversations with hundreds of parents and professionals. I believe these insights will be helpful to many, but primarily to unknowing and fearful parents, extended family, and the dedicated speech therapists who will find this expanded view helpful to their ongoing efforts to enhance the lives of those who stutter.

Additional credibility comes from the fact that I'm also the mom of a wonderful 26-year-old man who stutters.

My primary resources for finding participants were Facebook support groups for parents and individuals who stutter (including my own Voice Unearthed Facebook group). Following is the vocabulary I included in my request for participants (Appendix B):

- Did you or your child participate in speech therapy prior to age 7 and continued to stutter/stammer into their teen and adult years? What was helpful about that early therapy? What was not?
- Your story deserves to be heard. Please private message me (Doreen Lenz Holte, author of Voice Unearthed) through Facebook or send an email to voiceunearthed@gmail.com to complete a 10-minute Survey Monkey questionnaire and to be considered for inclusion in my next book.
- Help the world attain a broader view of the impact of early childhood speech therapy on those children who persist with stuttering/stammering and their families.

Once a person indicated an interest in participating, they were invited to complete a Survey Monkey questionnaire intended to gather information on:

- Age of the child or person who stutters (CWS or PWS)
- Selection process for intervention resources
- Assumptions relating to engagement in and components of therapy, and expected outcomes/goals

- Timeline of intervention(s)
- Therapist(s)' qualifications
- Types of therapy/therapy approaches
- Perceived response to and impact of therapy
- Interest in engaging in a Zoom (or in-person when possible) interview

Two versions of Survey Monkey questionnaires were developed— one for parents (Appendix C) and one for adults (Appendix D) who stutter. Once the survey was completed and there was agreement to do an in-person interview, a Zoom meeting was scheduled.

Approximately 65 individuals responded to my request for participants; I interviewed 60, several in person, but most utilizing Zoom. All interviews were recorded with permission and interviewees agreed to having those interviews represented in a book format.

This book tells the story of what I learned when I asked these individuals, 32 parents with children who stutter and 28 adults who stutter, to “tell me your story.” I specifically recruited adults and parents of older children who continued to stutter after early intervention (there are a few exceptions). I wanted to unearth the wisdom and knowledge that can stem from the long view of these experiences.

The comments and stories are presented anonymously to encourage candidness and honesty. I also felt it was important to protect the identity of children whose parents stepped forward to share their stories as those children have a right to tell their own story in their own time if they so choose.

Those interviewed included parents of younger children, pre-teens and teens, parents with adult children who stuttered, and adults who stutter. Although I requested parents of children who were older, I also interviewed several parents with younger children because they had a worthy story to share. I wanted to learn both what was helpful about childhood intervention and what was not helpful or even perceived as harmful.

Most I interviewed were from the US and UK, with several from Canada and Australia. There were no pre-planned questions; the interviews started with a simple, “Tell me your story.” Once the interviews were transcribed, I mined them for recurring themes and meaningful quotes, coded the themes and quotes, and amassed Excel spreadsheets to analyze and manage the data. This process of qualitative research and the recurring themes that emerged determined the framework of the book.

The contributors' willingness and passion to share and their openness around the joy and pain of their journey is integral to this conversation and to improving the quality of life for those who stutter.

Citations:

1. Carey, T., Stiles, W. (2015) Some Problems with Randomized Controlled Trials and Some Viable Alternatives, *Clinical Psychology and Psychotherapy*, 20 January 2015, <https://doi.org/10.1002/cpp.1942>, <https://onlinelibrary.wiley.com/doi/abs/10.1002/cpp.1942>

Appendix B: Call for Participants

Did you or your child participate in speech therapy prior to age 7 and continue to stutter/stammer into the teen and adult years? What was helpful about that early therapy? What was not?

Your story deserves to be heard. Please private message me (Doreen Lenz Holte, author of *Voice Unearthed*) through Facebook or send an email to voiceunearthed@gmail.com to complete a 10-minute Survey Monkey questionnaire and to be considered for inclusion in my next book.

Help the world attain a broader view of the impact of early childhood speech therapy on those children who persist with stuttering/stammering and their families.

Voice Unearthed II Parent Survey

1. Name: (For follow-up purposes only. Names and details will be changed in the book in order to maintain confidentiality.)

2. Email:

3. Current age of the child you're referring to (may be an adult by now):

4. Child's approximate age when stuttering/stammering was first perceived to be an issue:

5. Child's approximate age when they first engaged with a speech professional to address stuttering/stammering.

6. Child's age when formal therapy was discontinued (if discontinued)

7. How many therapists did your child see to address stuttering/stammering?

8. How did you select a therapist or therapists (check all that apply):

- Local clinic/geographic access
- Local school district
- Personal recommendation
- Through a professional support organization (i.e. NSA, FRIENDS, SFA, STAMMA, BSA):

Other (please specify)

9. What were the therapist(s) qualifications to treat stuttering (check all that apply)?

- Certified by a professional organization (ASHA, RCSLT, etc.) to treat stuttering/stammering
- Not certified by a professional organization
- Some or considerable experience treating stuttering
- Little if any experience treating stuttering
- Do not know/remember

Other (please specify)

10. What was the general approach used in therapy or therapies (check all that apply).

- Indirect - working with parents to adjust the environment to support fluent speech
- Indirect play therapy with parent and child
- Lidcombe Verbal Contingencies
- Stuttering Modification (goal of less tension utilizing speech tools, breathing, etc.)
- Fluency Shaping (goal of fluency utilizing speech tools, breathing, etc.)
- Counseling for child
- Counseling for parent

Other (please specify)

11. What was your child's reaction to therapy? Check all that apply.

- They loved going.
- They disliked going.
- They were neutral about going.
- They gained confidence in communication.
- They had fewer avoidance behaviors.
- They talked more.
- They talked less.

- They talked about the same amount.
 - They had less speech tension.
 - They had more speech tension.
 - They became more comfortable talking about their stutter/stammer.
 - You, as the parent, became more comfortable talking with them about their stutter/stammer.
 - They engaged more in outside activities.
 - They engaged less in outside activities.
- Other (please specify)

12. How were you, as a parent, engaged in the therapy process? If so, please describe your engagement. (Check all that apply.)

- I was included in the initial assessment.
 - I observed therapy sessions.
 - I actively engaged in therapy sessions.
 - I was updated at the end of a therapy session.
 - I was not involved in therapy.
 - I did homework/special time with them that included practicing speech tools and techniques.
 - I did homework/special time that did not include practicing speech tools and techniques.
 - I was instructed to make changes in the environment to promote fluent speech.
- Other (please specify)

13. How do you feel therapy for stuttering/stammering impacted your child?

- Decreased speech tension and stuttering behaviors.
- Increased speech tension and stuttering behaviors.
- Resulted in their talking more overall.
- Resulted in their talking less overall.
- Made them more comfortable with talking about their stutter/stammer.
- Made them feel more confident overall.

- Made them feel less confident overall.
- Increased avoidance behaviors.
- Decreased avoidance behaviors.

Other (please specify)

14. Would you be willing to have a one-on-one follow-up discussion with me to further explore and document your experiences?

Voice Unearthed Survey Teens and Adults April 2021

1. Name: (For follow-up purposes only. Names and details will be changed in the book in order to maintain confidentiality.)

2. Email:

3. Your current age?

4. Your approximate age when stuttering/stammering was first perceived to be an issue?

5. Your approximate age when you first engaged with a speech professional to address stuttering/stammering?

6. Your age when formal therapy was discontinued (if discontinued)?

7. How many therapists did you see to address stuttering/stammering?

8. How were your therapist(s) selected? Check all that apply.

- Local clinic/geographic access
- Local school district
- Personal recommendation
- Through a professional support organization (i.e., NSA, FRIENDS, SFA, STAMMA, BSA):
- Don't know/don't remember.
- Other (please specify)

9. What were the therapist(s) qualifications to treat stuttering? Check all that apply.

- Certified by a professional organization (ASHA, RCSLT, etc.) to treat stuttering/stammering
- Not certified by a professional organization
- Some or considerable experience treating stuttering
- Little if any experience treating stuttering
- Don't know/remember
- Other (please specify)

10. What was the general approach used in therapy or therapies? Check all that apply.

- Indirect - working with parents to adjust the environment to support fluent speech
- Indirect play therapy with parent and child
- Lidcombe Verbal Contingencies
- Stuttering Modification (goal of less tension utilizing speech tools, breathing, etc.)
- Fluency Shaping (goal of fluency utilizing speech tools, breathing, etc.)
- Counseling for child
- Counseling for parent
- Don't know/don't remember
- Other (please specify)

11. What was your reaction to therapy? Check all that apply.

- It depended on the therapy and/or the therapist. (Still check all that apply.)
- There were some aspects I liked and others I did not find helpful.
- I loved going.
- I disliked going.
- I didn't care either way.
- I don't remember.

Other (please specify)

12. What did you love and/or dislike about speech therapy?

13. How do you feel therapy for stuttering/stammering impacted your life?
Check all that apply.

- It depended on the therapy and/or the therapist (still check all that apply).
- Decreased speech tension and stuttering behaviors.
- Increased speech tension and stuttering behaviors.
- Resulted in my talking more overall.
- Resulted in my talking less overall.
- Made me more comfortable with talking about my stutter/stammer.
- Made me feel more confident overall.
- Made me feel less confident overall.
- Increased my avoidance behaviors.
- Decreased my avoidance behaviors.
- Helped me cope with negative reactions.
- Other (please specify)

14. Would you be willing to have a one-on-one follow-up discussion with me to further explore and document your experiences?

Appendix E: Additional Survey Question

(This question was asked in the first survey but required some clarification.) The SLP(s) qualifications to treat childhood stuttering included (check all that apply):

- general speech therapist (American Speech-Language-Hearing Association CCC-SLP certification)
- specialist in Fluency Disorders (American Board of Fluency and Fluency Disorders BCS-F certification)
- some or considerable experience treating stuttering
- little if any experience treating stuttering
- do not know/remember
- other (explain):