

the Out-of-Sync

Child

GROWS UP

Carol Kranowitz, MA

If you are seeking information about the effects of Sensory Processing Disorder (SPD) in children, you are in luck. An abundance of books is now available to help parents, teachers, and other non-occupational therapists learn to recognize SPD characteristics and support “out-of-sync” kids at home and at school.

Alas, should you want information about the effects of SPD as children mature, you will find fewer choices. Reader-friendly resources that describe “what happens next” are hard to write—and hard to find.

Whether they are wondering or worrying, parents and teachers have many questions about their kids’ futures. As children grow up:

- Do they grow out of SPD?
- Are they able to use their beautiful minds to flourish at school?
- Can they develop close friendships?

- Are they invited to birthday parties and social gatherings?
- Can they learn to enjoy games and sports?
- Can they manage noisy, odorous, madding places, such as the subway, the highway, the cafeteria, and the dormitory?
- Will they ever eat like other people?
- Do they learn to date, procreate, and parent?
- Do they find meaningful work?
- Does it ever become okay to hug them?
- Will it be possible to take them to new places? Go to the beach, across a bridge, to the amusement park, up an escalator, on an airplane ... to the dentist?
- Does everything turn out all right in the end?

Parents and teachers have asked me these questions since the publication of *The Out-of-*

Sync Child in 1998. They yearn for reassurance that the children they care for will develop the sensory skills necessary to function in daily life.

I have yearned, in turn, to give an answer more satisfying than, “It all depends ... I really don’t know.” I don’t know because, as an early-childhood educator, my expertise is with young children. Also, I do not know because I do not have SPD. Well, maybe just a little, when my hands come into contact with finger paints or bread dough. (Shudder.)

Because I don’t know firsthand how SPD affects maturing people, I have sent information seekers to experts who do. Sharon Heller, a psychologist, has sensory overresponsivity and has written books about it for teens and adults. Hartley Steiner, mother of three teenage sons with SPD, has assembled a compilation of memoirs from 48 adults.

Scholarly articles and research papers about SPD in adults are also available in journals, in OT Practice, in the American Occupational Therapy Association’s Sensory Integration Special Interest Section newsletters, and on the Internet. Moya Kinnealey

is well known for her research in adults with SPD, and Teresa May-Benson and Jane Koomar have more recently reported on research studies in this area. Tina Champagne has researched and published strategies on the integration of sensory approaches into mental healthcare practices with adults. Paula Aquilla wrote an excellent article for *S.I. Focus* about SPD in people of different ages.

These books and articles are helpful, and still we need more. Teenagers and adults must know that they are not alone, that they can learn new strategies, that others like them have learned to cope and improve their lives with direct one-to-one occupational therapy, and that the future is full of hope.

Thus, I decided to gather and interweave stories written by individuals who have lived with SPD all their lives and who are glad to tell us about the process. *Seeking Sync: Stories by Teens and Adults about Adapting to SPD* is the working book title. Sensory World will publish it in the fall of 2013.

To whet your appetite, here are some excerpts from the manuscript and thoughts from the contributors:

'I Was Finally Out of Jail'

“When I learned about SPD around my 40th birthday, I was shocked—so many years, so much suffering for me and others! I felt like a person who had been confined in jail for all those years, without being at fault, and suddenly I was exonerated because they discovered I was innocent.”

—Gina Beteck

'I Enjoy Helping Younger Kids'

“I have been pleasantly surprised to discover that although I am still a teenager, I am having a real positive effect on kids even younger than I am. One of the things I have learned is that although children can learn from the guidance of adults, they will progress even more if someone around their own age assists them. Through my speeches, I have been able to directly speak to children and convince them about the merits of hard work so they can find their own voices. This is a reward unto itself.”

—Alexander Fields-Lefkovic, author of books that promote exercise for kids with special needs

'I Learned to Attend to Personal Hygiene'

Dan Travis avoided tasks that involved the tactile sensations of soap and water until an occupational therapist helped him: “Even after my nervous system became more relaxed when I experienced these sensations, my mind was still psychologically hardwired to avoid them. I had to spend time working on removing my beliefs that these forms of stimuli would still be painful to me. Once I did, however, I was finally able to do the things I could never bear before!

“After undergoing more than 3 years of occupational therapy as an adult, I have finally gotten to a place where I am able to appreciate a daily shower, and brushing my teeth doesn't send me over the edge. I am now able to begin reversing an awful trend of declining dental hygiene. Even if I never truly enjoy these things, being able to do them without them wreaking havoc on me and sending me into a state of overload has been amazing.

“Occupational therapy honestly does have the potential to make dreams come true, and my story has been a living testament to that over the past few years.”



'I Help Others Understand'

After receiving a diagnosis of SPD, Rachel Schneider decided to inform her relatives about her condition prior to a cousin's wedding: "I cried when I wrote the e-mail, unsure of how I would come across, how they would react, and how it might change our relationships. Their reactions were heartwarming. When I showed up at my cousin's celebration

"Most people don't know how much you go through until you give them permission to understand."

(disorders and diagnoses be damned), my uncle enveloped me in his arms. He didn't need to speak a word—I knew he understood. My aunt and cousins followed suit.

"Two hours later, when I started feeling sensorially taxed by the day's events, no one asked, 'Why are you going? Why can't you stay?' Instead, we all teared up and hugged each other good-bye. They thanked me for the enormous efforts I put forth to be able to participate in the celebrations that night. And that's the thing. Most people don't know how much you go

through until you give them permission to understand."

The stories I have collected so far cover many topics, from feelings to friendships, from strategies for avoiding certain sensations to strategies for adapting to other sensations, from childhood memories to future plans. Several topics re-occur, especially the misery of having an "invisible" and often undiagnosed or misdiagnosed disorder—and the jubilation when an occupational therapist assigns a correct diagnosis of SPD. The stories are vibrant, poignant, funny, determined, angry, resigned, tender, and grateful—the full gamut. Indeed, the contributors concur that their lifelong work to manage sensations has made their lives and relationships more precious than anyone would have predicted when they were out-of-sync children.

Want to add your voice? Please do—and soon. Seeking Sync is still in progress. Send your contact information to SeekingSync@SensoryWorld.com—and let's get in sync! ♦

References

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Additional Resources

You can check out Moya Kinnealey's research studies on SPD in adolescents and adults at www.SPDFoundation.net. I also recommend Teresa May-Benson and Jane Koomar's research studies on sensory processing in typically developed adults and those with SPD, available at www.thespiralfoundation.org/researchproj.html.

In 1995, Carol created a course of study about her interest in SPD and turned her master's thesis into a book, The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder, which was published in 1998. Carol is a board member of the SPD Foundation. Her website is www.out-of-sync-child.com