



Science in Autism Treatment

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Dedicated Issue

Celebrating the Legacy of Dr. Tristram Smith

Introduction by David Celiberti and Peggy Halliday

and a collection of tributes by some of his colleagues and family.

It was with great sadness that we share that Dr. Tristram Smith passed away on August 6, 2018. There are many people in the field who contribute with great abundance to the scientific literature about autism treatment. Many others in the field are staunch advocates for science-based treatment and best practices. Still others are generous with their time and talent while working in small, detailed, but incredibly important ways. Tris was all of those people.

It is hard to imagine that one man can accomplish all that he has with respect to conducting and publishing research, supporting an array of nonprofit organizations such as ASAT, mentoring young professionals, and sharing his knowledge and expertise with even the most seasoned. His contributions have been nothing short of transformational, his impact is far reaching, and the tremendous gap his untimely death leaves the autism community is palpable.

Tris was an incredible and beloved member of ASAT's Board of Directors and will be deeply missed. He served since the very beginning of our journey to promote evidence-based autism treatment, initially as a member of our Professional Advisory Board and then on our Board of Directors from 2005 until his

death. We have long appreciated Tris' compassion, humility, and sense of humor. We wish to honor his legacy and contributions to the field with a collection of tributes. We invited some past and current members of our Board, some of his co-workers from the University of Rochester, colleagues from his past, as well as his wife and daughter. Common themes in the tributes to Tris Smith are that he was a man of integrity and incredible intellect, he was unfailingly good-natured and kind-hearted, and he was someone you could always count on. We experienced that in every single interaction that we had with Tris, right up until his death. If there was a question about some obscure autism treatment almost no one had ever heard of, Tris knew about it. He was never too busy to point us, with objectivity and clarity, to any existing research (or lack of research) with the greatest efficiency and patience.

We, at ASAT, have an endless amount of gratitude for all he created and all that he has shaped. Tris has been a mainstay of ASAT and he will be missed by every one of us. We stand on his shoulders. As we look to the future, we hope to carry on his commitment to science and to individuals with autism and their families as that is the least we can do to honor such a great man!

Table of Contents

A collection of tributes to Dr. Tris Smith	<u>2</u>
Research Summaries:	
RT of Social Skills Groups at School	<u>16</u>
Cognitive Enhancement Therapy for Adult ASD	
36th Annual Autism New Jersey Conference	<u>20</u>
Interview: Dr. Todd Harris and Amanda Duffy	<u>23</u>
Is There Science Behind That? Fecal Microbial Transplantation	<u>27</u>
A Note of Thanks	<u>30</u>
From the Archives: Clinical Corner - Explaining Treatment Decisions to Others	<u>31</u>
How ASAT Supports Journalists	<u>33</u>
Treatment Summary: Bleach Therapy	<u>36</u>
Sponsorship Campaign	<u>38</u>
Sponsors	<u>39</u>
Donor Wall	<u>40</u>
ASAT's Helping Hands	<u>41</u>

TRIBUTE TO TRISTRAM SMITH, PhD, BCBA-D

Jenny Katz, Tristram's wife and mother to Jonah and Maddy *Words Spoken at the Service*

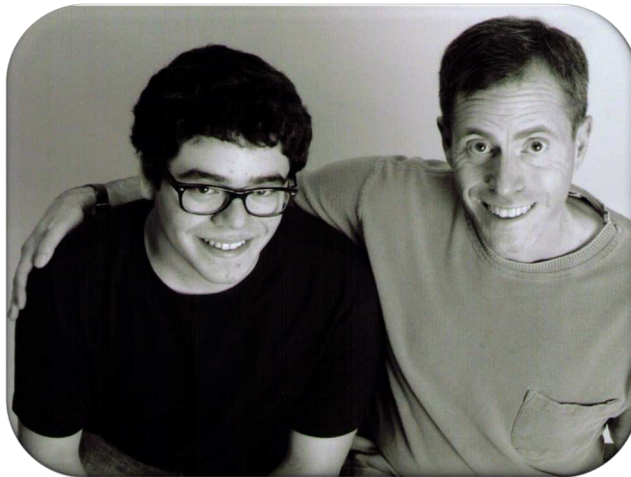
And now, I want to say some of my own words to honor Tristram. Many of you know that Tris has always been supremely committed to his goals and also to the people in his life. With regard to work, he seemed tireless. He sat for hours upon hours, pecking out grant proposals, manuscripts, chapters, and reviews with an amazingly fast two fingered typing technique. He gave countless talks. He took classes and read widely to keep up with new developments in the field and to do his part in contributing to innovation. He was a brilliant man who also worked incredibly hard to try to make a difference in the world. He was especially motivated to make the world a better place for children and their families.

Do you know how Tris and I first met? He interviewed me for a job at Washington State University. He seemed very serious and very hard to read. I couldn't tell what he was thinking, and he didn't really answer my questions. It was frustrating. It turns out, he was desperately unhappy there, but of course he didn't want to say so during my interview. It was NOT love at first sight. I definitely didn't feel any kind of intimate connection. He struck me as very polite, professional restrained, serious, and remote.

Fast forward later, and I am living in Washington State. We were friends for almost two years before our first date. So how did I fall for Tris? By watching him play with his young son, Jonah. Tris repeatedly taunted and threatened Jonah with "THE CLAW" – "you better watch out you, its going to get you,

it's coming....., it's coming...." Jonah was enthralled. The first time I told Tris that I loved him was on Halloween, in 1999. Tris was stylishly dressed up as Mr. Watson to accompany Jonah as Sherlock Holmes. I'm sorry not to have been around when he was the Robin to Jonah's Batman. We married after dating for only a few months. You know what kind of people do that? Celebrities. Not me – just him -- Tris was an absolute rock star. And Halloween is my favorite holiday.

Tris was full of gentle humor. He loved puns, including "What language do germs speak? German?" Tris also developed humorous nicknames for Jonah and Maddy over the years. Jonah loved basketball and so was called Michael Jonah. When Baby Maddy joined our family, he positively glowed with love and pride. We still call him the baby whisperer. When Maddy toddled around the park, arms out, face raised to the sun, she was called Julie Wen Yong Andrews. When she was grumpy, he called her "surly girly" but always with great affection. Tris loved to take the kids to the farmer's market, to the Park Ave and Clothesline Festivals, and on bike rides. He read to each of them, every single night, for over ten years. He cooked delicious meals for all of us. At one recent dinner, he asked 15 year old Maddy if she had eaten any salad, the only vegetable he was serving. She balked. Tris asked her what the word for "health" was in Spanish. "Salud," she said, with triumph. Tris beamed. He said, "Salud – see the connection? Eat salad."



Tris and son Jonah

(Continued on page 3)

(Continued from page 2)

Tris used humor to cope. We laughed all the time, at everything. At one point in my career, I had a boss who would yell short angry phrases at me. Jenny. Why you call? Why not meet? You are bad. Bad. I'd complain to Tris, who would send follow up emails to me written in the voice of my boss. Jenny. When you come to dinner? Come home. Home. Over his life, and particularly over the last 3 years, he's had many serious medical problems. He texted me countless updates about his cardiac health, always with references to love songs. Tris would say things like "the doctor says my heart will go on, like Celine Dion," and "we have to listen to my heart before it's too late." On his last trip to California, just days ago, he sent me a selfie of himself at a Cancer Survivor's park with the caption "Staying Alive, Staying Alive."

Tris saw others clearly, including our flaws, but he believed that people are fundamentally good. I think it's a form of projection. He was so loving and generous with others. He was absolutely decent, down to his bones. A few years ago, we watched a TV show, Fargo, where a man with an orange coat was being hunted. This man sent his girlfriend out wearing the orange coat, knowing she would be the target instead of him. Tris was as wide eyed and incredulous as I've ever seen anyone be about anything – his jaw was literally dropped open. He'd never even dream of letting me, or anyone else, take the fall for him!

I can't tell you how secure and loved he made me feel in that moment. I can't express how much he made me



Tris and his family

feel secure and loved -- in all of our moments. He showed his boundless romantic heart in countless big but also little ways over the 18 years, 2 months and 2 days of our marriage, making me coffee every

morning, letting me steal all of our covers each night. Tris was the best man in the world and the most adoring father to our beautiful children. And along with Jonah and Maddy, he is the absolute great love of my life – I could not be more proud to be his family, his spouse. He was ours, and we have been the very luckiest family.



Tris with his children—Summer 2018

Maddy Katz, Tristram's daughter

Part of her Father's Day Card in 2015 (at age 12)

1. I love your smile.
2. We always have the best time together when we play outside.
3. I love getting your advice on life.
4. You have the most handsome haircuts (?)
5. Thanks for encouraging me to do my homework.
6. I'm glad I got your wisdom.
7. I love how you always say, "I know all."
8. If I had to describe you in one word, it would be old-ish.
9. Because of you, I learned to swim.
10. I love how every day you read to me.
11. Yeah, you were right about well...everything.
12. I admire your dedication to your work.
13. I am amazed by your ability to be smart.
14. I love that you taught me to appreciate exercise.
15. You cook the best asparagus ever.
16. I wish I had known you when you were a kid.
17. I love remembering the time you took me to the Strong Museum and the Zoo.
18. I love going with you to Chicago, Texas, and other states.
19. Your hugs are always slightly bony.
20. It's fun to cheer on Super Bowl games with you.



Tris and daughter Maddy

21. I value your advice about life.
22. I love listening to mom singing with you.
23. I'll always be grateful for your advice.
24. Nobody else can sing like you.
25. It makes me smile when you lose things.
26. If you were a car, you'd be a convertible.
27. It means so much that you showed me how to ride a bike.
28. I love that you love my personality.
29. I love hearing stories about your childhood.
30. I'm so lucky that you're my dad.

Scott Wright, President and CEO, Lovaas Institute for Early Intervention *Three Moons Over My Hammy*

“Three Moons Over My Hammy, all with fries, and more coffee, please.” In a long list of surreal moments I have had over many years with Ivar Lovaas and Tristram Smith, this food order, placed at a Denny’s in Canyon Country, California started a conversation that is near the top of that list.

Ivar was suffering greatly from Alzheimer's disease at that time. Tris was in town, and I drove him out for a visit. Ivar LOVED Moons Over my Hammy, and so that would just have to be Tris’ and my order also. The two men exchanged small talk for a while. Ivar possibly recognized Tris, but their long history was not present to him at the time. Ivar asked, “Are you two friends?” “Yes,” I replied, “With you... because of you!” The food arrived, and Ivar was instantly delighted. We sat quietly for a few more moments, “Do you two work together?”, “Yes, but not as long as you and I have worked together,” replied Tris. Ivar then furrowed his brow, and peered at Tris intently, reached out his hand, Tris took it, and they stared at each other for a few seconds more, holding hands. Ivar welled up a bit, and then his lip quivered. A flood of emotion was obviously overwhelming him as recognition and love for Tris returned to him. Tris looked at Ivar, breathed heavily, and then just nodded an affirmation, obviously feeling the same emotions. “Oh yah, such a hard worker...such a hard worker...” Ivar trailed off, then exclaimed, “You wrote a lot!”

Ivar REALLY loved Tris, and Tris loved him right back. That moment, at Denny’s perfectly sums up how I am feeling about Tris as I write this. His work

is certainly astoundingly important, a fact that is easy to support with a mountain of data, but for me, it was his heart that impacted and touched me the most. He was an intellectual giant for sure, but more importantly, he was a gentle, caring, and beautiful soul. You could always count on good and thoughtful advice, either about life or work, from Tris. I only understood him about half the time, but that was beside the point. This man, that I loved and respected as a personal hero, seemed to, for some reason, love and respect me back. I know that there are countless stories and feelings out there from his family, friends, and colleagues exactly like mine. Tris was so generous and thoughtful with his time and energy with virtually everyone. We all loved him, and he loved us right back!



Tris’s College Graduation

Tristram Smith’s most obvious professional legacy is the massive positive impact his research has had on the lives of children with autism. We are right to stand in awe of that legacy. But for me, the massive positive impact he has had on my life, and the lives of countless other friends and colleagues is also his professional legacy.

I have a few times in the past years found myself going to Denny’s and ordering Moons Over My Hammy to warmly remember Ivar and that moment years ago. I will in the future place that same ridiculous order,

“Moons Over My Hammy, with fries, and more coffee, please,” only next time it will be to also fondly remember the brilliant, gentle, caring, and beautiful soul of my friend, Tristram.

Catherine Maurice, Author, ASAT Founder, and Member of the Professional Advisory Board
Remembering Tris

I met Tris Smith almost 30 years ago, I believe, when I flew out to Los Angeles to participate in a conference and he was a graduate student at UCLA. I remember not much about our conversation - only my initial impression of a gentle young man, soft-spoken, friendly, a bit shy. A few years later, our paths crossed again when my co-editors and I, working on Behavioral Intervention for Young Children with Autism and aware of his growing reputation for serious scholarship, invited him to contribute a chapter to that publication. That chapter, "Are Other Treatments Effective?", established in my view the intellectual rigor, integrity and courage of Tris Smith. In the fierce "autism wars" that I have written about elsewhere, he was not afraid to speak the truth about the extent and the quality of research behind so many interventions claiming to help people with autism.

He was humble and thoughtful about his own discipline, which revolved around applied behavior analysis, and recognized that it could not be considered a panacea for the challenges associated with autism. He ended his chapter with us on the hope that in the future other interventions would be developed that could help more people diagnosed with autism reach their fullest potential to lead an independent life. But he was equally clear-eyed about the ever-increasing parade of dubious fads and fallacies that had little to no basis in solid research and bled money and time from vulnerable families.

Casting a calm, objective eye on these claims, his work became a valuable tool for people who wished to make informed decisions. And when I say "courage" it is not an overstatement. Anyone who dared challenge some of the claims surrounding Facilitated Communication, Auditory Integration

Training or mega-doses of various vitamins - to give but three examples out of dozens and dozens - risked various forms of harassment, intimidation, and public criticism. But I never heard him excoriate anyone in personal terms or respond to any attack with anything less than objectivity and clarity. In the time that I was privileged to work with him, I saw a man steadfast in focus - a man of compassion and principle who had chosen to live a life in service to others, and to the truth.



Dr. Tristram Smith

Kathryn Dobel, J.D., Law Office of Kathryn Dobel, Berkeley, California

I first met Tris Smith in 1989 at UCLA, when he was the Senior ABA Therapist for my young client's applied behavior analysis (ABA) educational program developed and implemented as part of Ivar Lovaas' graduate seminar course. At that time, the initial Lovaas research was just being published, and research-based ABA programs were only available through Ivar's graduate seminar classes through the Clinic for Behavioral Treatment of Children at UCLA. It was a few years later that ABA programs were available in northern California on a workshop model with UCLA students traveling back and forth. My clients in 1989 had to rent an apartment near UCLA to access the program as they lived in San Jose, CA.

Though I had by then been representing children with disabilities in my private practice in Berkeley, California since about 1981, I still knew very little about educational programs that were effective for clients on the autism spectrum. I knew as soon as I met Tris that he was both knowledgeable in the methodology that worked and could effectively explain it in lay and expert terms, and would need to be the witness from UCLA at our hearing if the case did not settle. I did not know at the time that the case (Union School District v. Smith) would take five years to conclude after prevailing at hearing and defending appeals all the way to the U.S. Supreme Court, but Tris donated his time for the duration, dedicated to my client and to the science behind the effective programming developed at UCLA at that time.



Tris and ASAT's Board—2011 Annual Meeting

I could not have presented ABA research in a meaningful way in a hearing without Tris' kind and patient assistance and unbelievable memory for detail during testimony. After we prevailed in California, Tris evaluated children and testified about the science of ABA programming in Washington, Oregon, Nevada and multiple localities across the country where he and I were able to consult on or participate in efforts to gain precedent setting decisions for early intervention in educational programs through the early 1990s across the country. No matter where Tris was working or the status of his health, he made himself available and was selfless in his dedication to advancing the research and increasing potential for learning for children impacted by autism.

I honor the important work that Tris Smith accomplished during his life, including by working with children and families and their advocates, and through published peer reviewed research papers and replication studies of his original work with Ivar Lovaas. When Tris asked me to participate on the Board of the Association for Science in Autism Treatment (ASAT), I gladly joined the organization whose Board he had joined early on and served on until his death. Tris will remain an inspiration always, and his efforts to research and advance the analysis of effective treatments for autism will be greatly missed.

Jill Aldrich, MS, BCBA, Division of Developmental and Behavioral Pediatrics University of Rochester Medical Center

When I heard the terrible news of Tris' passing, I was with my daughter and we were on our way back from a beach weekend. I told her that my first reaction was how sad I was that I wouldn't ever be able to tell Tris what he meant to me and to our family. I feel a lot of sadness for his wife, Jenny, his son, Jonah and daughter, Maddy – more than I would be able to adequately express. I feel sad for our Division at the University of Rochester and all of my colleagues who want the magnitude of his work on behalf of children with autism to never cease making gains. There was/is so much of his unfinished work here, and at times I have felt sadness and anger that he will not be able to finish it.

The idea of Tris Smith came into my consciousness before I was his colleague, before I was a behavior analyst. I knew of him before I had the pleasure of meeting and working for him. It was when my husband and I were looking for papers on Early Intensive Behavioral Intervention for young children with autism back in the mid-1990s. We were challenging our school district in semi-rural Virginia about what constituted an appropriate education program for our then 4-year-old son. Tris' work was the foundation of our position with our school district and the findings of his research have helped countless families in the same boat. It's impossible to calculate how many children were helped in a tangible way by the work done by Tris over the years spanning his career. Our son is now 26 and without it, I can't imagine where he would be.

Despite how sad I feel at this overwhelming loss, I am filled with gratitude for knowing Tris. I am grateful for his good nature and can attest that his colleagues adored his very presence in the office. He never felt that he was too important to participate in the smallest thing; never was too busy, nor too important to engage. He was such a kindhearted man and positive to a fault. I never heard a disparaging thing said by Tris about anyone and there were plenty of times when someone most assuredly deserved it. I am grateful for his tenacity in caring about other people.



Tristram Smith

As our research director, Tris was very aware that his work writing grants to further his work also had the by-product of keeping a staff of people employed and receiving health benefits. He considered these needs and took this responsibility very seriously. I will also be forever grateful to him for advising and mentoring me through my Master's program and BCBA certification as he's done for scores of others. How lucky are his students, post-docs, mentees, and interns to have had his teaching, training and advisement?

More than all of these things, though, I am most grateful for his friendship. He always made time to have a personal chat. He was a super busy man, but we managed to talk about so many things and his ability to remember minutiae about my family amazes me. His desire to make improvements for people, whether a child with ASD or a coworker or a stranger, is a rare attribute that few share. He was truly, truly special. I am so grateful to have known him and I will miss him forevermore.

Daniel W. Mruzek, PhD, BCBA-D
Associate Professor of Pediatrics
University of Rochester Medical Center

I met Tristram Smith on a snowy day in February 2002. I had flown in to interview for a junior faculty position at the University of Rochester Medical Center, and he was on my interview schedule for late afternoon. I knew Tris by reputation prior to meeting him because his studies on autism spectrum disorder (ASD) intervention were watershed events in the field. Indeed, I had recently participated in impassioned debates on their ramifications in the circles of my Ohio State graduate program, and I was primed and ready to meet one of the “greats”. As I entered his office for that interview, Tris greeted me with his disarming smile, teased me about Rochester’s “alluring” February weather, and, in his soft-spoken conversation, initiated a discussion on the work we had in front of us. I felt right at home with Tris on that cold February day, as well as over the subsequent 16 years. I’m sure, many other people feel equally blessed to have known him as well. With Tris, one felt respected and valued. Tris was a kind, gentlemanly, principled colleague.

Working with Tris, one had opportunity to see the field of autism intervention from a unique vantage point. He had that rare ability to see over the horizon and share his view with others. Despite his busy schedule, Tris found time for all who wanted to see him, and he freely discussed impactful ideas and fresh insights. Otherwise mundane events, such as waiting for a delayed flight or driving to an appointment, might turn into a new research project, an intervention approach, or book chapter; and we always found something to laugh about. With Tris, one learned “process skills”, like how to focus, formulate questions, spin hypotheses, access resources, connect lines of inquiry, test ideas, and disseminate findings to others. He did all of this with the kind of humility that was, ironically, the byproduct of his wisdom. With this outlook, he allowed for my mistakes, helped me course-correct as needed, and celebrated success. Tris recognized that the application of science should be a very humane undertaking, both in practice and outcome. He had an unparalleled ability, a discipline, really, to keep his eye on the prize: effective interventions for persons with autism and their families. He modeled how to behave as a true scientist and as a gracious ambassador of the field to others.

His mentorship did not end with our science. Actually, it began there and then extended to the broader aspects of our lives. Tris provided a singularly powerful example of how to treat others kindly. Whether with international research experts, an undergraduate volunteer who wanted to talk about opportunities in the field, or young parents grappling with a new diagnosis, Tris was an incredibly patient listener who provided practical, usable advice that gave others reassurance and clarity. When vexed with a problem, one was likely to walk away from Tris thinking, “My problem may not be completely solved, but I know what to do next, and I think it’s going to be OK.” The



Tris and ASAT colleagues—ABAI 2011

pride and love he had for his son, Jonah, and daughter, Madeleine, as well as his wife, Jennifer, was, simply put, profound. He treasured his marriage and his family, and, anytime he was asked, “How’s the family doing?” one could hear this in his response.

My last message to Tris was a standard “office message” indicating I would need to reschedule a meeting with him, due to unexpected demands. I wish, instead, I would have texted this: “Tris, you are a fine example of a person for others, and you have been a true friend. I’ll endeavor to carry on your legacy of science and service. You, sir, have made a profound, positive impact in my life. Thank you.” Alas, I can only record that message here.

Eric V. Larsson, PhD, LP, BCBA-D

Executive Director, Clinical Services

The Lovaas Institute for Early Intervention - Midwest Headquarters

We owe a lot to Tris Smith, not the least of which for the massive volume of work that he produced in his career. The following bibliography of published research papers always impresses us by its length, depth, and scope. Personally, what also always impresses us, is when we think we've had an innovative idea, we discover that he's already published on it. Here are "a few" themes that are worth noting.

His first four publications were all on highly significant issues that persist to this day. All of these publications were also with leaders in the field. The first publication was a comprehensive behavioral theory of autism, accompanied with a plan of research that he was able to follow throughout his career. Soon after, he published a paper on a lasting challenge to ABA – the problem of overly simplistic dissemination of ABA through the means of workshops, with little in the way of a systematic organizational behavior management plan to back them up. Then he moved into the deep technique of ABA in exploring functional and equivalence class development. Finally, the first four are rounded out with the essential follow up report on Lovaas' 1987 research participants.

From there, he looked at the generality of EIBI with other populations, and of less intensive EIBI. These papers, in combination with his additional research on intensive high-quality replications, truly fleshed out the generality of ABA with autism treatment. He rounded out this exploration with his work on meta-analyses of EIBI.

At the same time, he continued to look at the fine-grained methodology of the field, studying focused approaches to generalization, language programming, social programming, creativity programming, and parent-training.

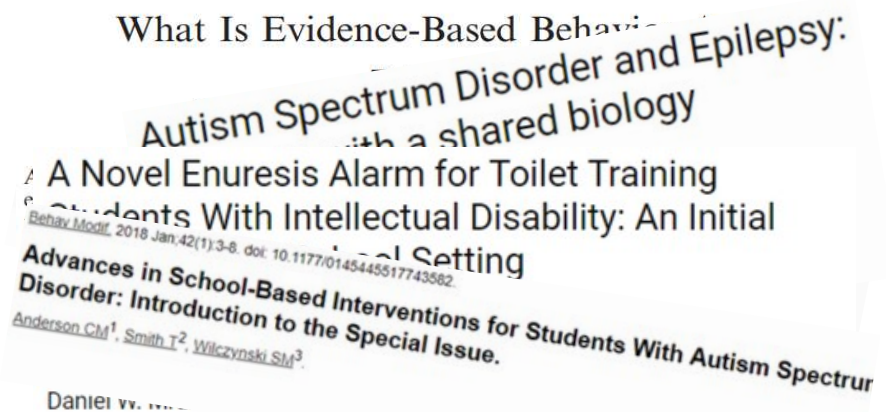
From there he began to be increasingly sought out by biomedical researchers, and those who were explor-

ing the rules of evidence, and thus began a very high output of research in those realms. It is fitting that his last publication, two weeks before his untimely end, came full circle to a solid replication of his original work with Lovaas.

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Who was this man, who could work so incisively and diligently across the spectrum of important issues in autism? How wonderful for us that we could be his beneficiaries.

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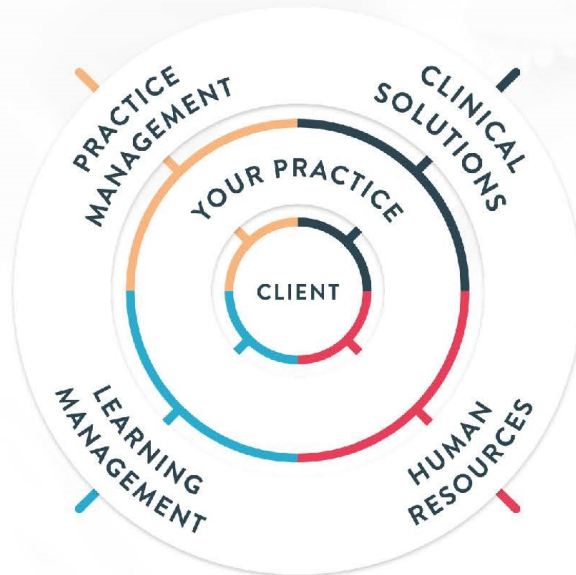
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RESEARCH SUMMARIES

A Randomized Trial of Social Skills Groups at School & Cognitive Enhancement Therapy for Adult Autism Spectrum Disorder

In August, we lost our dear colleague, Dr. Tristram Smith, at the age of 57. For over 15 years, Tris was a beloved member of ASAT's Board of Directors. He was a significant figure to all of us, generous with his time and expertise and unmatched in his ability to synthesize the scientific literature on autism intervention. Even in the last week of his life, Tris continued to offer his wisdom and guidance to his ASAT colleagues. He even reviewed the two summaries that follow. Both summaries focus on adults with ASD who, we know, have been studied far less often than children with ASD. The first study looked at the effects of a particular social skills intervention on social skills and social anxiety. The second study examined the effects of cognitive enhancement therapy on variables like processing speed and attention, understanding emotion, and amount of competitive employment. In memory of Tris, we offer you these summaries with the hope that more and more research will include adults with ASD.

Karen Fried, PsyD, BCBA-D
Research Synopses Co-Coordinator

McVey, A.J., Dolan, B.K., Willar, K.S., Pleiss, S., Karst, J.S., Casnar, C.L....Vaughn VanHecke, A. (2016). A replication and extension of the PEERS® for Young Adults social skills intervention: Examining effects on social skills and social anxiety in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46 (12), 3739-3754.

Reviewed by: Tristram Smith, PhD,
ASAT Board of Directors

Why research this topic?

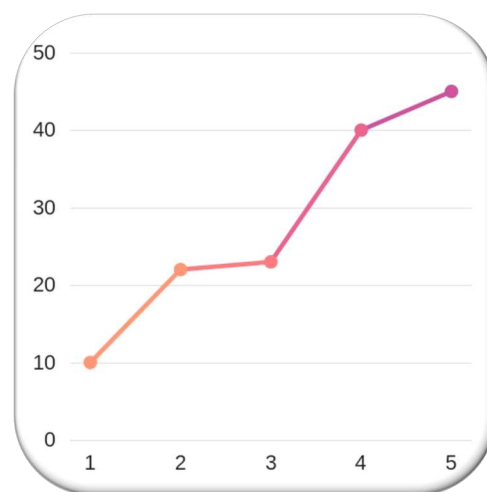
Individuals with autism spectrum disorder (ASD) show significant deficits in social cognition such as recognizing mental states in others, reading social cues, and empathizing. These deficits interfere with social interactions and ongoing peer relationships, which may lead to feelings of loneliness. Although starting in childhood, the deficits extend into adulthood. However, most research on social skills intervention has focused on children. One program, the

Program for the Education and Enrichment of Relational Skills (PEERS®) for Young Adults developed by Gantman, Kapp, Orenski and Laugeson (2012) has some empirical support for improving social skills in young adults with ASD, but, until now, all research has been conducted within the UCLA clinic where the intervention originated. The current authors set out to conduct an independent evaluation of the effects of the PEERS® for Young Adults on social skills and social anxiety in young adults on the spectrum.

What did the researchers do?

Fifty-six participants were included in the study. Participants were required to have a diagnosis of ASD confirmed through the Autism Diagnostic Observation Schedule, be between the ages of 18 and 28, have a parent report of social difficulties,

(Continued on page 17)



(Continued from page 16)

speak English and have parents who speak English, and be free of a comorbid psychiatric diagnosis. Participants were randomly assigned to either an experimental or waitlist group. Intervention for the experimental group consisted of 90-minute sessions, once per week, for 16 weeks of the PEERS® for Young Adults, as outlined in the treatment manual developed at UCLA. Trained graduate students served as group leaders and trained undergraduate students served as assistants. Intervention sessions consisted of small group didactic instruction, role-plays, behavioral rehearsal, coaching and practice through social skills homework. Topics included having appropriate conversations, choosing friends, communicating via social media, handling arguments, and coping with bullying or teasing. Parents of participants also received intervention in separate sessions. At entry into the study, and again after the experimental group completed intervention, participants and parents in the experimental and waitlist groups completed rating scales to assess social skills, social cognition, empathy, loneliness and social anxiety.

What did the researchers find?

Following intervention, the PEERS® for Young Adults group surpassed the waitlist group on measures of social skills, social responsiveness, understanding of social concepts, empathy, and problem behaviors. Unfortunately, improvements in rates of loneliness were not obtained, possibly because rates were already low prior to treatment. Despite not being directly targeted by PEERS® for Young Adults, significant decreases in self-rated social anxiety were obtained post intervention. Although not directly studied, the authors discuss several possible reasons for the improvement in anxiety.

What are the strengths and limitations of this study?

This study was the first known independent replication of treatment effects of the PEERS® for Young Adults. Supporting past results, the authors reported improvements in social skills, social cognition, empathy and peer interactions in young adults with ASD as assessed through parent and self-ratings. In addition, it was the first study to show reductions in

social anxiety using PEERS® for Young Adults. The study used a strong experimental design, used multiple measures of outcome, and ensured adherence to the PEERS® manual by trained clinicians. The authors do, however, highlight several limitations to their work. First, is the lack of diversity of their sample. Participants were mostly male, Caucasian young adults. A second limitation is the lack of third party, independent raters. Pre and post ratings were all conducted by participants and parents who were not blind to treatment. Third, the study would have been improved if a direct measure of social behavior was used in place of, or in combination with, rating scales. A final limitation was the absence of a long-term follow-up.

What do the results mean?

The current study helps fill the need for empirically supported social skills treatment programs for young adults with ASD. PEERS® for Young Adults improved social skills, social knowledge and social anxiety in a group of these adults.

Eack, S. M., Hogarty, S. S., Greenwald, D. P., Litschge, M. Y., Porton, S. A., Mazefsky, C. A., & Minshew, N. J. (2018). Cognitive Enhancement Therapy for adult autism spectrum disorder: Results of an 18-month randomized clinical trial. *Autism Research, 11* (3), 519-530.

**Reviewed by: Tristram Smith, PhD,
ASAT Board of Directors**

Why research this topic?

Cognitive remediation has been shown to be effective in treating neuropsychiatric conditions such as schizophrenia, attention deficit hyperactivity disorder, and traumatic brain injury. This approach may also be useful for individuals diagnosed with autism spectrum disorder (ASD) because these individuals have lifelong cognitive deficits, particularly in processing complex social and non-social information. The current study is the first controlled evaluation of the efficacy of cognitive remediation in individuals with ASD. It focuses on adults, who have been studied much less often than young children with ASD.

(Continued on page 18)

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What did the researchers do?

Participants were 54 adults aged 16-45 years old, with an ASD diagnosis confirmed by the Autism Diagnostic Observation Schedule-Second Edition or the Autism Diagnostic Interview-Revised, and with significant social and cognitive deficits as assessed by the Cognitive Styles and Social Cognition Eligibility Interview. The participants were randomly assigned to receive 18 months of either Cognitive Enhancement Training (CET), a cognitive remediation approach that integrates computer-based neurocognitive training with group-based training in social cognition, or Enhanced Supportive Therapy (EST), which focused on psycho-education and condition management. The participants were assessed every 9 months by trained interviewers and testers who were blind to the treatment assignment. Outcome measures included assessments of neurocognitive ability (e.g., processing speed and attention), social cognition (e.g., understanding emotion), and amount of competitive employment. Analyses of outcome were based on data from all 54 participants.

What did the researchers find?

The researchers found that the CET group improved over time on all outcome measures. Also, neurocognitive ability and competitive employment improved significantly more for participants in CET than for participants in EST. However, social cognition improved more for the EST group than for the CET group at the 9-month assessment, though this difference was no longer significant at the 18-month (end of treatment) assessment.

What are the strengths and limitations of the study?

The study was one of the first to evaluate an intervention for adults with ASD and to focus on an approach that has been successful with other neuropsychiatric conditions (cognitive remediation). Participants were randomly assigned to the CET and EST groups. Independent testers who were blind to group assignment found that CET improved neurocognition in the adult participants diagnosed with ASD. Outcome measures included assessments of functional improvement, particularly employment, which increased significantly more in the CET group than in the EST group, indicating that CET produced broad gains.

The authors indicate that results should be interpreted in light of the small sample size, which was restricted to young adults, limiting generalizability to older adults. The only aspect of social cognition that was measured was emotion processing, preventing conclusions about the effect of CET on other social cognition outcomes. Another limitation is that the study did not examine how improvements in cognition led to higher rates of employment; other variables likely contributed to increased employment.

What do the results mean?

Cognitive remediation shows promise for improving cognitive impairments in adults diagnosed with ASD. CET was effective for enhancing neurocognitive function, especially in the areas of attention and processing speed. This improvement has the potential to increase quality of life in adults living with ASD.

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Come see why many professionals and caregivers return each year to Autism New Jersey's conferences. This year, the 36th Annual Conference will be held on October 18th and 19th at Harrah's Waterfront Conference Center in Atlantic City. Since they can be confident that the workshops and exhibitors have been vetted for scientific support, 1,200 participants are again expected for more than 70 workshop choices, 100 autism-specific exhibitors, a poster session exploring new research, and networking opportunities galore. With so many options, there is specialized material pertaining to individuals of all ages and support needs, with a focus on practical strategies.

Workshops range from basic to advanced, with topics applicable to family members as well as professionals from various fields and levels of experience. Presenters include expert clinicians, self-advocates sharing their experiences, teachers and therapists in both public and private arenas, attorneys and financial planners, and seasoned parents—some of whom are social media sensations! No matter your role in the autism community, the conference experience can be customized to your unique needs; whether your goal is to focus on early intervention, educational strategies, transition, adult supports, financial and legal advocacy, your professional skills, or caregiver support, you will find current and credible information and resources at this conference.

Meaningful Content

The conference will begin with the keynote address, Parent-Professional Collaboration: How to Promote Meaningful Communication on Difficult Topics, from Robert LaRue, Ph.D., BCBA-D (Rutgers University, Douglass Developmental Disabilities Center) with Eileen Shaklee ("Autism with a side of fries" blog). It continues with workshops explaining best practice for challenging behavior, communication, and social, vocational, and life skills as well as those offering family support. Examples include making lessons more engaging, incidental teaching, reducing restraint/seclusion, self-regulation, simplifying data collection, stress management (for students and teachers), and a transition curriculum. Content specific to adults ranges from functional life skills to vocational training to preparation for college and careers, plus housing, sexuality, legal and financial issues, and more. Quality of life is also a priority: toileting, feeding, anxiety, social communication, stress management, and increasing independence are just a few of the issues which will be addressed.

Additional Highlights

- Discuss the latest findings with the researchers themselves at our poster session, sponsored by the Association for Science in Autism Treatment (ASAT). New for 2018, the Rutgers Center for Adult Autism Services is sponsoring an Adult Autism Research Competition; the winner will receive a \$1,000 fellowship and briefly share his/her findings during the conference keynote.

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- Continuing education credits are offered for behavior analysts, speech-language pathologists, psychologists, and more. BCBA's will find five options for ethics credits and two for supervision.
- A Parents-Only Networking Lunchroom will be available both days. One area will be facilitated discussion with psychologist and parent, Dr. Leslie Newport, and the other area will be unstructured.

What Participants Say

- "WOW, what a great conference! There's a great level of energy by everyone there. It's such an engaging and informative event."
- "As a parent and a professional, I learned quite a bit! I've been to a lot of autism conferences, and yours is one of the best organized and most informative."
- "The workshop options are an excellent mix for all. I meet so many wonderful people and always learn something new!"
- "Thank you for providing an exceptional exhibitor experience. What a terrific networking opportunity!"
- "Every year, I utilize the information to support both parents and colleagues to help our students. I learn a lot I can directly apply, and the resources are phenomenal."

Register Today

Late registrations will be accepted until October 12th with a \$50 late fee. There are a limited number of discounted rooms available at Harrah's. Onsite registration also will be available with the late fee. Contact Elissa Kapp at 609.588.8200 x13 or ekapp@autismnj.org with any questions. Caregiver scholarships are available as funds allow; contact conference@autismnj.org to apply or consider donating if you are able. Learn more about this conference by visiting www.autismnj.org.

About Autism New Jersey

Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them. Through awareness, credible information, education, and public policy initiatives, Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. We are grounded in science, strengthened by knowledge, and devoted to creating a society of compassion and inclusion for all those touched by autism. Services are not exclusive to New Jersey residents; all are welcome to contact the Helpline at 800.4.AUTISM or information@autismnj.org, access free publications, and participate in our Autism Ambassador awareness campaign, Annual and Transition conferences, and other workshops.

Established by a group of parents more than 50 years ago, Autism New Jersey is proud to be a resource for individuals, families, professionals, government officials, the media, and concerned residents who all turn to Autism New Jersey for reliable information, compassionate support, and evidence-based training.



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INTERVIEW

**With Dr. Todd Harris, Executive Director of Autism Services,
Devereux Advanced Behavioral Health and
Amanda Duffy, Program Director, MEd, BCBA,
Devereux Advanced Behavioral Health Pennsylvania**

**Maggie Haag, MEd, LSW
ASAT Lifespan Content Co-Coordinator**

Q. Employment for individuals with autism and/or intellectual disabilities is currently a major focus of adult serving systems nationally, however, many service providers struggle to build strong program models for employment support for this population. Can you briefly describe your program model for supported employment and customized employment? What type of staff training do you provide?

A. Our Community Adult Autism Partnership Program (CAAPP) is a highly individualized approach designed to capitalize upon a participant's unique strengths and interests that will lead to successful employment. CAAPP is a program that falls under Devereux Autism Services in Pennsylvania. Our one-to-one program model weaves evidence-based approaches with the skills and interests of each individual and the needs of employers.

The key to success of the CAAPP model is comprehensive staff training with a focus on using evidence-based instructional practices in employment settings. Staff are also trained on an individual participant's learning and behavior support protocols. A behavior analyst monitors how well staff implement these protocols. In addition to clinical trainings, staff also receive guidance and support on managing specific employment issues, such as maintaining positive relationships with employers, developing natural supports for the individuals on-site, and fading assistance. Equally important is staff training on building independence in community skills, self-determination, quality of life issues, appropriate socialization with co-workers, and so on. Finally, our staff are supported to become good communicators. Success for the individuals we serve is often dependent upon staff being able to navigate complex situations and effectively communicate to address issues.

Q. What is your process for assessing appropriate employment options for the individuals you serve?

A. A comprehensive assessment prior to employment drives placement. Staff complete a thorough record review to identify a participant's history of supports, volunteer work, employment experiences, and areas that have been successful in the past -- as well as what has not gone so well. Situational assessments, team interviews, direct observation and preference assessments are used to outline the participant's preferences, strengths, and abilities. It also helps identify areas in which the participant displays little interest or does not currently have the skills to perform successfully.

This discovery process provides a guide in identifying a good employment match. For example, if the participant prefers a setting where they are not expected to interact with others, this may rule out working in the front of a restaurant as a server or busser, but working in a kitchen may be an option.

Q. There is a lot of discussion surrounding preparing individuals for employment, but less about sustaining employment once an individual obtains a job. What are some strategies that can be used to help an individual not only obtain, but maintain a job?

A. There are some key components that should be in place that will pave the way for long-term employment success. Some of these include a comprehensive evaluation of an individual's ability to work independently and a plan in place on how to address any issues that may arise in the future. For example, if the individual's job responsibilities were to change in the future, what supports can the employer provide to the individual to help them successfully navigate those changes? Will the participant know how to access additional natural supports in the workplace when needed?

(Continued on page 24)

(Continued from page 23)

When it is evident that the employment opportunity is a good fit, supports should be reduced gradually in an organized manner, as opposed to being removed abruptly. During this process, more naturalistic supports and strategies will continue, such as task lists and visual reminders. We work closely with supervisors and co-workers to make sure they are comfortable and confident in the supports that are continued. If co-workers and supervisors are unsure of their role or unaware of supports, keeping a job becomes more difficult.

Equally essential to maintaining employment are frequent and regular check-ins between the individual and the employer; between the individual and our program staff; and between the employer and our program staff. We have found that these check-ins allow for proactive and preventive problem solving to occur before smaller issues become larger ones. As our program staff members begin to fade their presence on-site, these check-ins become even more important.

Q. We all hit “bumps in the road” at work, such as getting a task we have never done before, or getting a new boss. How can we support individuals with autism at work through these bumps in the road?

A. One of the limitations of community employment is that the focus is often on reducing job coaching support as quickly as possible, without a clear plan as to how to address potential issues that may arise. Initial discussion with the individual, the employer and relevant team members should include what supports are available for the individual should they encounter obstacles down the road. For example, if the individual is expected to learn a new job responsibility, can a job coach be re-implemented temporarily with a clear plan to gradually reduce job coaching support to assist the individual with the new skills?

An important strategy to prevent the bumps from becoming mountains is educating employers in general about individuals with autism and the specific needs of the individual employee. We help employers to understand what events may be difficult for the individual to cope with, and how-to problem solve before the event occurs. For instance, if the employment site needs building renovations for a few days and there is the expectation of loud noises,

what can be done to lessen the impact of the noise? Can the employee listen to music with headphones? Can a white noise machine play in the background? These are the type of options that should be discussed and implemented.

Finally, we work to improve each participant’s own problem-solving skills, reducing the need to rely on others to identify and solve problems as they arise.

Q. How can professionals prepare and support the employer to support their worker with autism? What type of education have you and your team provided to community partners to ensure buy-in?

A. When approaching employers on behalf of our participants, we strive to outline the individual’s strengths and abilities. While we are often focusing on supporting our participants, there also needs to be a focus on educating and transferring skills to the employer so that support can continue in the absence of a job coach or employment specialist.

It’s important to start by having a quick “Autism 101” at your fingertips. Assess what will be important for the employer to know about individuals with autism that may be helpful in the long run, but also what might be relevant to the particular job site. Having a quick information sheet to share with employers that clearly and efficiently outlines the potential benefits of hiring individuals with disabilities (e.g., tax incentives) is also an important tool. Include resources for the employer to learn more or who they can contact with questions.

In 2012, we developed a short web-based training for employers in partnership with Pennsylvania’s Bureau of Autism Services. The training informed supervisors and co-workers about autism and some basic strategies that have been shown to be helpful in supporting individuals with autism in the workplace. These strategies included providing visual information related to schedules and expectations; how to best address introducing changes in workplace routines and/or new work tasks; how to create a comfortable and positive work environment; and various environmental and sensory strategies that can be used. We have found this type of training to be highly beneficial, especially when it is adapted to audience characteristics and the length of time available for training.

(Continued on page 25)

(Continued from page 24)

Q. We have all had jobs that haven't worked out for a variety of reasons. How do you help an individual with autism determine if their current job is a good fit for them if they are having difficulty, and how do you assess when it may be time to begin looking for an alternative job?

A. Regular check ins are incredibly important. If a job isn't a good fit, it may be a small adjustment that is needed – but we need to learn about it early, before it creates bigger issues. Helping participants identify what is going well in a job and what they wish they could change is a good starting point when job satisfaction begins to wane. Something as simple as listing likes and dislikes about a job can lead to identifying issues that can improve the workplace experience.

This process of evaluation also creates an opportunity to teach problem solving and social skills. For example, if a participant lists that he is sitting too much at work, we problem-solve with that individual to see if more active tasks can be added to the routine. Once those active tasks are identified, we will strategize on how to get to that change, beginning with scheduling a time to meet with the supervisor. Through role play and practice, we can review how that conversation with the supervisor might go, and how to best react to the supervisor's response.

However, as with anybody, sometimes there isn't a compromise that would make the job a good fit. If the job cannot be modified in a meaningful way, it is important to begin seeking alternatives without a sense of blame or shame for either the participant or the employer. Sometimes, it just isn't a good fit.

Q. What are the biggest barriers to ongoing, successful competitive employment for adults with autism in your experience?

A. One of our biggest challenges is teaching participants the social skills that are needed to be successful in community-based employment sites. For most of their lives, our participants are in very structured environments and surrounded by trained staff. So, they learn social skills within those types of contexts.

Learning appropriate social skills in environments that are significantly less structured and predictable,

and being around co-workers who often have received no or very little training, creates some instructional challenges. And social rules vary between settings, so we must continuously evaluate and prioritize what skills are the most important to teach that can be generalized across a variety of situations and settings.

Having multiple community-based job training experiences during the transition years provides an opportunity to teach these critical skills in the natural environment and to also teach flexibility with rules as new job training sites are introduced. Unfortunately, many of our participants may not have had these opportunities in their earlier years. This requires us to prioritize skills to work on, as not all skill areas can be addressed at one time.

Q. What advice do you have for employers who may be hesitant to hire an employee with autism?

A. First and foremost, we believe that this is not only an opportunity for the individual seeking employment to be a contributing member of our community, but an equally important opportunity for employers to demonstrate their commitment to the community.

But, realistically, we know that there are barriers – some that are perceptions and some that are very real. The best way to overcome barriers is to personalize the process. We make sure that the employer has an opportunity to get to know the individual they are considering hiring. Along with face-to-face meetings, we have found that digital and/or paper-based portfolios can also serve to achieve this goal. The digital portfolios can be particularly helpful since it allows the potential employer to see the individual at a past work site and to recognize their capabilities. Video references or letters of reference from past employers or supervisors at training sites can also be very valuable. Having a past supervisor describe work habits, punctuality and attendance, attention to detail, stamina, and other relevant information is helpful in bridging doubts about including an individual with autism in the workplace. These references frequently emphasize how much participants have taught their co-workers and how they have improved the social elements of the workplace.

(Continued on page 26)

(Continued from page 25)

Secondly, clearly communicating our role is critical in building an employment opportunity. We have found that employers are put at ease when we explain that we will be on site to support the new employee in learning the related job tasks and routines before we gradually fade support. We also emphasize our continued partnership with the participant and employer to address work related issues, both small and large.

On a broader level, our goal is not only to find meaningful employment for the individuals we serve but to educate employers on a larger scale about the potential of those we serve and how employers can get involved. Some employers may not be ready to hire, but are open to allowing participants to come observe the work setting, ask questions, and possibly practice skills on site for assessment and teaching purposes. We have a small business that initially offered participants the opportunity to practice work skills on site. Not only did this open doors for participants to get much needed experience, but the opportunity to have participants observe and practice skills has led businesses to be interested in hiring people with disabilities too!

For anyone, finding a job can be a daunting task. For those we serve, it's often a bigger climb. But the rewards are equally magnified – both for the individual and the employer. Individuals with autism sharing their life with co-workers and supervisors ultimately leads to a more inclusive and diverse workforce and stronger communities.

Based on our interview, it sounds like training and education for employers is just as important as it is for the individuals supported at work. Dr. Harris and Amanda, thank you very much for your thoughtful and informative answers to my questions about this important topic.

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IS THERE SCIENCE BEHIND THAT?

Fecal Microbial Transplantation

Thomas Zane & Kathleen Holehan

Department of Applied Behavioral Science, University of Kansas

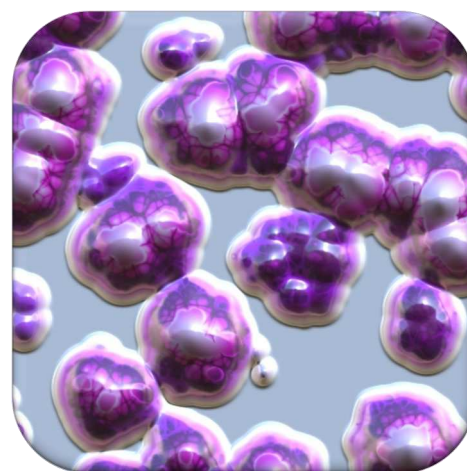
As the incidence of autism spectrum disorder (ASD) continues to rise, treatments continue to be developed. A search for interventions yields two different approaches towards treatment – social/psychological/educational and medical. Examples of the former include applied behavior analysis (ABA), social skills training, and special education. One example of a medically-oriented treatment is Fecal Microbial Transplantation (FMT) which is the subject of the present column. What is FMT, how is it used, and can it be considered an evidenced-based practice?

The basic theory behind FMT to treat autism goes something like this – for some reason, the intestines of individuals with autism would be producing bacteria that are not native to the intestines and function as toxic agents (Finegold, et al., 2002), which then produce the symptoms of autism. To recover the health of the intestine, fecal matter (from a healthy donor) is “transplanted” into the gut of the individual with autism, which purportedly then transmits the good bacteria into the gut of the individual with autism and begins the process of destroying the toxic bacteria and replacing it with healthy bacteria. This, then, would alleviate the symptoms of ASD. Thus, the sequence of events are:

- (1) the intestines of individuals with autism are assumed to be filled with bad bacteria;
- (2) the bad bacteria causes the symptomatology of autism; and
- (3) transplanting healthy fecal matter into the affected intestines will result in improvement in the symptoms of autism displayed by the individual.

The first recorded use of FMT was noted in fourth century China, for the treatment of diarrhea and food poisoning (Zhang et al., 2012). Since then, the procedure has been used in the medical community with

specific medical illnesses, such as clostridium difficile (CDI; e.g., Brandt, Aronidis, Mellow, et al., 2012). There is a vast medical literature reporting on the role of intestinal bacteria in health (e.g., Panda, Guarner, & Manichanh,



2014; The Human Microbiome Consortium Project, 2012; Ursell, Metcalf, Parfrey, et al., 2012). Generally speaking, medical procedures are conducted to collect intestinal bacteria which are treated to a variety of laboratory procedures to determine the type, extent, and health of the bacteria found in the samples. Several studies have been published that purportedly show a wide variety of intestinal bacteria across a number of diseases, including Irritable Bowel Disease (IBS; e.g., Frank, Amand, Feldman, et al., 2007), obesity, (e.g., Kriegel, Sefik, Hill, et al., 2011), cardiovascular (e.g., Brown & Hazen, 2015), arthritis (e.g., Scher & Abramson, 2011), and multiple sclerosis (e.g., Ochoa-Reparaz, Mielcarz, Ditrio, et al., 2009). Based upon these laboratory findings across studies, FMT has been used to transfer healthy bacteria (from healthy donors) to the intestines of an ill individual, in the hopes that the healthy bacteria in the fecal matter will spread into the intes-

“The basic theory is that the intestines of individuals with autism would be producing bacteria that are not native to the intestines and function as toxic agents (Finegold et al., 2002), which then produce the symptoms of autism.”

(Continued on page 28)

(Continued from page 27)

tines of the recipient and replace the bad bacteria with healthy ones, resulting in improved health. Methods of transplanting the fecal matter include direct infusion into the GI tract via colonoscopy, enemas (Persky & Brandt, 2000) or swallowed in capsule form (Kelly et al., 2015).

Relationship between Intestinal Health and ASD

Finegold et al. (2002) suggested that the use of antimicrobial products (medicines and other substances that kill or inhibit the growth of microorganisms, such as bacteria and fungi) could impair or alter indigenous intestinal flora and thus allow organisms that produce a neurotoxin into the body. This neurotoxin may be related to the development of autism, since some parents report the onset of autism to a time closely approximating the use of antimicrobial products (Sekirov et al. 2010). In other words, Finegold and colleagues, and Bolte (1998) are suggesting that, at least for individuals diagnosed with ‘late onset’ autism, the establishment of the syndrome could be due to the use of antimicrobial medication, which kills the typical (and harmless) bacteria in the intestines, which then allows the development of other intestinal bacteria that produces a neurotoxin, which then produces the symptomatology of autism. Further support comes from Finegold et al. (2002) who compared the makeup of intestinal bacteria of individuals diagnosed with autism and individuals with no diagnosis of autism, showing a greater number of unhealthy bacteria in the systems of the individuals with autism.

Evidence to Support Using Fecal Matter Transplants to Treat Autism

To date, there is little empirical evidence supporting the hypothesis that unhealthy intestinal bacteria is causally related to the diagnosis of autism, or that FMT is causally related to improvement in autism symptomatology. The First International Symposium on the Microbiome in Health and

“FMT has been used to transfer healthy bacteria (from healthy donors) to the intestines of an ill individual, in the hopes that the healthy bacteria in the fecal matter will spread into the intestines of the recipient other individual and replace the bad bacteria with healthy ones, resulting in improved health.”

“Fecal matter transplants should not be used as a treatment for autism, since they fall into the category of unproven treatments without empirical research support.”

Disease with a Special Focus on Autism was in 2014 (www.microbiome-autism.com). The presentations at this conference were published in the journal *Microbial Ecology in Health and Disease* (2015; volume 1). These

papers discussed the conceptualization of a disease model of autism, the possible role of gut problems in the syndrome, correlational data related to the level of bacteria in individuals with and without autism, and a discussion of future clinical research on this topic. As of this writing, there is no empirical study using acceptable research designs or controls showing any causal link between FMT and alleviation of any challenges exhibited by individuals with autism. There is one case study reported by Aroniadis and Brandt (2013) that involved ‘observations’ of five children diagnosed with autism after FMT; however, this was not published.

Conclusions

Currently, there is no research support for the hypothesis that an unhealthy gut causes autism. There is no research support for the hypothesis that FMT results in improvement in autism symptomatology. To date, there is a vast number of medical studies focusing on the level of healthy bacteria in the intestines of individuals who are healthy and individuals who have a number of illnesses, including neuropsychiatric ones. However, those are all correlational in nature, with no empirical proof. Thus, one must be cautious in linking unhealthy intestinal bacteria to autism. It is not yet known whether or not the unhealthy bacteria is the cause of autism, or whether the existence of autism causes the unhealthy bacteria. At this point, we must consider the state of this science as at the ‘descriptive’ and ‘predictive’ levels. What remains to be determined is if there is any causal relationship between gut problems and the onset/improvement of autism.

References to gut problems elicits thoughts of Andrew Wakefield, who was one of the first authors to present this hypothesis of gut-brain connection. Wakefield –

(Continued on page 29)

(Continued from page 28)

and his original theory – has been thoroughly discredited. Acceptance of these current hypotheses must wait for thorough vetting through science before any confidence in the validity of them can be established. Up until that time, fecal matter transplants should not be used as a treatment for autism, since they fall into the category of unproven treatments without empirical research support. The use of proven, empirically-supported treatments still remain the best approach towards solving this complex syndrome.

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A Note of Thanks

Laura Shay MEd, BCBA, SLPA

Our heartfelt thanks to graduate students from Touro College's Behavior Analysis program and their Program Director, Dr. Karrie Lindeman who raised \$1,075 for ASAT. They all participated in a fundraiser to support ASAT and its mission to disseminate information about science-based treatment.

Students teamed up to sell cookie dough throughout their summer semester. Student representative Victoria Ruocco worked diligently to ensure the students were not just selling cookie dough, but ensuring that others became aware of the information available on our comprehensive go-to website.

We are very excited to hear that there are plans to make this an annual fundraising event. We hope that other programs throughout the country help us get the word out that science matters in every single conversation about autism treatment. Thank you Dr. Lindeman and Touro students!



“Fundraising is not just a means of raising money, but also a way to promote the message and goals of an organization you support. The decision to support ASAT, an organization whose mission is to promote safe, effective, science-based treatments for people with autism was an easy decision. We made sure that each and every fundraising participant and customer was educated on ASAT’s purpose and why ASAT is so important. By raising more awareness, there is hope that more families become more knowledgeable, and adopt these evidence-based treatments”

Victoria Ruocco, MS
NYS Certified School Psychologist
Registered Behavior Technician

FROM THE ARCHIVES

Explaining Science-Based Treatment Decisions to Friends and Family

David Celiberti, PhD, BCBA-D
Pamela F. Feliciano, PhD

Although ABA is the treatment for autism with the most scientific support, in today's world, families are constantly hearing about some "miracle cure" or "cutting edge" treatment. Often with the best of intentions, loved ones may offer advice or suggestions regarding treatments that are not scientifically validated. Families who make a commitment to science and choose evidence-based treatments may find it difficult to navigate these discussions. In this installment of *From the Archives*, Drs. David Celiberti and Pam Feliciano offer a few suggestions on how to respond to these well-intentioned suggestions, and better articulate the basis of choices made and the role that science should play in the treatment of autism.

Caroline Simard, MS, BCBA
From the Archives Coordinator

We certainly respect any individual's right to his or her own opinion, and certainly for parents of children with autism to make decisions for their child regarding treatment; however, we believe that scientific evidence and the use of objective data should guide treatment options for all diseases and conditions, and autism is no exception. The late Senator Patrick Moynihan eloquently said, "Everyone is entitled to their own opinions, but not their own facts." It is simply a matter of fact that theories, hypotheses, and testimonials do not provide adequate information to guide treatment decisions.

When friends or acquaintances hear about our experiences with autism, it is still the case that quite often the first thing they ask is, "What is your opinion of vaccines?"; despite the retraction of Andrew Wake-

field's article by the Lancet (a very rare occurrence by this highly reputable journal). Sadly, the vaccine debate has long distracted the autism community from important discussions such as how best to help children already diagnosed with autism realize their fullest potential and live a happy and meaningful life.

In an ideal world, all treatment providers would make a commitment to science and evidence-based practices, and all members of the journalism community would make a commitment to responsible journalism. Until these ideals become established as the norm, those who do understand science-based treatments must do what they can to inform and educate others about the benefits of scientifically validated treatment, and the use of data to guide decision-making when assessing the benefits of any and all treatments.

Although applied behavior analysis is the treatment for autism with the most scientific support, we are rarely ever asked our opinion of this therapy, or if it is effective. Instead, every few months or so, some "new" treatment (or "repackaging" of a known treatment) will gain the attention of consumers. Given the large numbers of television reports, newspaper articles, blogs, and websites putting forth "miracle cures" and "breakthroughs," it is not surprising that parents frequently receive advice and suggestions from extended family members, neighbors, and co-workers, particularly after a news item is broadcast, printed, or otherwise disseminated. Many of these individuals have the best intentions and are eager to share what they believe is "cutting edge" information about autism. In other cases, the advice is sometimes provided in a manner that comes across as critical of what you are choosing to do or not do for your child (i.e., it may be implied that you are not doing enough as a parent to help your child with autism).

(Continued on page 32)

(Continued from page 31)

If the information is offered by a more casual acquaintance, it may be best to simply thank him or her for their interest and concern and move on; however, such a strategy may not fare as well with individuals with whom you have a closer relationship. In these cases, you might consider sharing the following:

- There are dozens of “miracle cures” and “breakthroughs” (i.e., pseudoscience) for autism that manage to receive widespread media attention, even if they have not been proven effective. In fact, there are over 500 treatments touted to address autism;
- It is important to be critical of all available information, regardless of the source, and to recognize that not all information on the Internet is reliable and accurate;
- There is a large body of scientific research published in peer-reviewed journals and carried out by hundreds of researchers that supports the choices that you have made;
- Numerous task forces (some are listed at the end) have looked closely and objectively at the available research and have determined that the vast majority of autism treatments lack any scientific support and, in fact, some may be harmful;
- Autism treatment is a multi-million dollar industry, and many treatment proponents rely heavily on sensationalism and extraordinary claims to “sell” their products;
- Interventions that are actually shown to be the most effective often receive the least amount of media attention; and
- For most other medical conditions, a provider that disregards proven intervention and uses a fringe treatment may actually be sued for malpractice (you may even consider drawing an analogy to a medical condition of particular interest to the person providing the advice).

Of course, you may also consider addressing this matter proactively. This would involve clarifying your choices and commitment to science-based treatment to more significant family members and friends on your terms and at your convenience. It may be helpful to view this tactic as a series of tiny conversations. You may even consider sharing links to websites such as the [Association for Science in Autism Treatment](#) (ASAT), which will help your family members and friends separate the wheat from the chaff. We would like to draw your attention to a few sections of ASAT’s website that bear relevance to this discussion.

- [Learn more about specific treatments](#)
- [Summaries of published research articles](#)
- [Making sense of autism treatments: Weighing the evidence](#)
- [Recommendations of expert panels and task forces](#)

Finally, ASAT’s newsletter, [Science in Autism Treatment](#), is a free publication, so encourage your friends and family to subscribe.

It is our hope that the information shared above may help your friends and family better understand the role that science should play in the treatment of autism, the need for objective data to drive decision making, how to better identify pseudoscience, and perhaps most importantly, why parents must be such savvy consumers.

HOW ASAT SUPPORTS JOURNALISTS

Erin Leif, David Celiberti, Maithri Sivaraman, Renee Wozniak

It can be challenging for journalists to sift through all of the literature and media content related to autism treatments. In this article, we will be sharing information about the Association for Science in Autism Treatment (ASAT) and suggesting ways you might navigate the perils of a field fraught with pseudoscience and misinformation. It is our hope that you and your colleagues within the journalism community may find ASAT's resources interesting and helpful in our shared commitment to keep science and evidence at the forefront when discussing autism treatment.

ASAT was established in 1998 as a not-for-profit organization of parents and professionals committed to improving the education, treatment, and care of people with autism. With a mission to promote safe and effective science-based treatments for people with autism, ASAT disseminates accurate, timely, and scientifically sound information while advocating for the use of scientific methods to guide decision-making and combating unsubstantiated, inaccurate, and false information about autism and its treatment. Our newsletters and website can provide journalists and other media professionals with numerous resources to make reporting on safe and effective autism treatment easier.

Why is accurate reporting on autism treatment important? There are currently over 500 different marketed interventions for autism, with the vast majority lacking any scientific support. However, these treatments are often showcased as “miracle cures” and “breakthroughs.” When autism treatments without any scientific support are sensationalized, families may be lured into spending tremendous time and money on ineffective (or potentially harmful) treatments. But this need not be the case. Families deserve accurate, science-based information about autism treatment, and your role as a journalist is critically important in helping concerned family members and other consumers make the best possible treatment choices for their loved one.

For this reason, it is important that researchers, clinicians, and journalists rely on a scientific framework to promote effective communication and collaboration.

Members of the media need quick access to accurate, up-to-date, science-based information about specific autism treatments, but it can often be difficult to cull this information from the pages of scientific journals (which are often locked behind paywalls and filled with technical terminology). It is our hope that this article serves to provide a comprehensive list of resources offered to journalists and other members of the media, to ensure that scientifically sound information about autism and its treatment is free and accessible. We anticipate this list of offerings will continue to grow, and with it an expansion of opportunities for collaboration.

We would like to take this opportunity to share details about four important ASAT initiatives that may be helpful to you as a journalist:

Published Newsletter: ASAT publishes a quarterly newsletter, [Science in Autism Treatment \(SIAT\)](#), containing reviews of published research, books, and consumer resources (e.g., training videos, websites), interviews with leaders in the field of autism treatment and advocacy, answers to questions about important clinical issues related to treatment, strategies to differentiate evidence-based options from others marketed as panaceas, guidance to media professionals, and more.

(Continued on page 34)



(Continued from page 33)

Website: ASAT's website (www.asatonline.org) provides valuable information about weighing the evidence supporting various treatment options. ASAT regularly updates [treatment summaries](#) and [research synopses](#) so readers may access timely information about the current state of autism intervention research in an easy-to-read format. Each treatment summary includes a brief description, an assessment of the scientific research supporting or refuting that treatment, and key references for more information. The website features book reviews, interviews, topical articles, and information to assist with a variety of clinical issues. In addition to pages for members of the media, the website also contains pages specific to special interest groups such as parents of newly diagnosed children, medical professionals, and teaching faculty. Finally, you can find links to the current newsletter, [Science in Autism Treatment \(SIAT\)](#) as well as past issues in the [Archived Newsletters](#) section.

Media Watch: ASAT's [Media Watch](#) initiative identifies, highlights, and shares published information about autism and autism treatments. Understanding that every media contribution has the potential to reach thousands of consumers and service providers, we support accurate media depictions of empirically-sound treatments for autism. We also respond to inaccurate information of proposed treatments reported and, at times, promulgated by news outlets. In our experience, inaccurate portrayals of autism treatments in the media often involve, but are not limited to:

1. Exaggerating the research support for an intervention for which no, or too little research exists;
2. Ignoring the research basis that may already exist for the treatment in focus;
3. Disregarding the relevance of science altogether;
4. Disregarding position statements from various professional organizations that warn against or discourage the use of a particular treatment; and
5. Failing to acknowledge research that does NOT support a particular intervention.

You can review our [200+ published letters](#) written in response to autism news in the media.

Specialty Pages for Media Professionals: We have created a [section](#) on the homepage of our website for members of the media community. Additionally, [guidelines](#) are provided for journalists to help you tackle your next autism story from a science-minded and conscientious perspective. Please also familiarize yourself with [our FAQ section](#). Although this list of frequently asked questions is a work in progress, we hope that you can find some responses to recurring questions here. We will be dividing questions and their responses into the following 4 sections:

- FAQs about Autism
- FAQs about Intervention Delivery
- FAQs about Media Representations
- FAQs about Research

In the remainder of this article, we would like to draw your attention to some specific resources that bear relevance to your important work:

ASAT's Online Resources Specifically for Journalists

- [Autism Treatment in the Media](#)
- [Questions to Ask the Marketers of Autism Treatments](#)
- [Questions to Ask Before Writing the Next Story](#)
- [Resources of Journalists: Ten Websites Supporting Science Journalism](#)
- [Characteristics of Quality Autism Websites](#)

ASAT's Website: Resources Pitched to Consumers of Media Representations (Family Providers, Treatment Providers)

- [Ten Resource for Consumers to Evaluate Information Sources](#)
- [Expand Your Science Knowledge...Relate it to Autism Treatment...And Be a Savvy Consumer!](#)

(Continued on page 35)

- [Caveat Lector: Let the Reader Beware](#)

ASAT's Website: Other Relevant Links

- [The Pitfalls of Testimonials](#)
- [ASD Intervention: How Do We Measure Effectiveness?](#)
- [Underwater Basket Weaving Therapy for Autism: Don't Laugh! It Could Happen...](#)
- [The Persistence of Fad Interventions](#)
- [Treatment Summaries: What Works, What Needs More Research, & What Doesn't Work](#)
- [Characteristics and Qualities of Autism Websites](#)

How You Can Help Us

- Encourage others to sign up for our [newsletter](#) and peruse the sections of our website.
- Emphasize in your articles how essential it is for consumers to make careful choices guided by the best available scientific research.
- Please keep in mind that April is Autism Awareness month and we are available to contribute content to your stories specific to promoting awareness about best practices.
- We would be very interested in your feedback on this article. You can reach us at [me-
dia@asatonline.org](mailto:media@asatonline.org).

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TREATMENT SUMMARY

Bleach Therapy

Amanda Bueno dos Santos, BS, BCaBA and David Celiberti, PhD, BCBA-D

Description: Bleach is typically used as a hard surface disinfectant, a germicide, and for bleaching textiles. It has been used as a treatment that involves a mixture of water, chlorine dioxide (ClO₂), and citric acid¹ taken in on a regular schedule. With respect to route, individuals drink, ear drop, eye drop, spray on the skin or nose, or administer as an enema. Providers of the product claim that Chlorine dioxide has the ..."impressive ability to selectively choose between healthy & diseased tissue - doing so by actively removing electrons from diseased tissue & pathogenic stressors"². This treatment comes in different names: Miracle Mineral Supplement³; Master Mineral Solution⁴; or the Chlorine Dioxide Solution protocol⁵. When ingested, MMS can be caustic to the digestive tract and the Food and Drug Administration has received reports of severe side effects such as a low blood pressure, nausea, vomiting.



Research Summary: There are no controlled research studies on this treatment. Chlorine is toxic, poses significant risk of harm, and is potentially lethal, particularly for young children.

Recommendations: Bleach Therapy is not recommended as a treatment for autism spectrum disorders. Bleach therapy appears implausible and unacceptably risky and should not be consumed by humans.

Selected References

Systematic reviews of scientific studies: There are no controlled research studies on this treatment. The evidence is anecdotal and relies 100% on uncontrolled testimonials.

Selected scientific study: See above.

Selected reports of side-effects:

DeFilippis, M., & Wagner, K.D. (2016). Treatment of autism spectrum disorder in children and adolescents. *Psychopharmacology Bulletin*. 46 (2), 18-41.

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Position Statements and Warnings:

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(Continued on page 37)

(Continued from page 36)

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- National Autism Society of the United Kingdom (2016). Retrieved August 14, 2018 at www.autismsociety.org/statement-genesis-ii-church-health-healing.

Related ASAT articles:

Celiberti, D., & Lorelli, D. (2012). Underwater Basket Weaving Therapy for Autism: Don't Laugh! It Could Happen. *Science in Autism Treatment*, 9(4), 8-10.

Harrison K. L., & Zane, T. (2017). Focus on science: Is there science behind that? Bleach therapy *Science in Autism Treatment*, 14(1), 18-24.

Related Media Watch letters:

[Bueno, A., & Wozniak, R. \(2018\). ASAT Responds to The Journal.ie's, "HSE Staff Member Accused of Feeding Their Child Bleach Solution 'To Cure' Autism"](#)

[Celiberti, D., & Pritchard, J. \(2018\). ASAT Responds to Newsweek's, "Parents Are Making Their Children Drink Bleach to 'Cure' Them of Autism"](#)

1. Rivera, K. (2018). *MMS – Master Mineral Solution*. Retrieved from <https://cdautism.org/mms-master-mineral-solution>
2. MMS Products International (2018). *Frequently Asked Questions*. Retrived from <https://mms-healthyliving.com/FAQ's.html>
3. MMS Products International (2018). *Home*. Retrieved from <https://mms-healthyliving.com>
4. Humble, J. (2016). *MMS Health Recovery Guidebook*. Retrived from <https://jimhumble.co/bookstore>
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PROFESSIONAL SPONSORSHIP INITIATIVE

Does Your Agency Share ASAT's Values?

ASAT believes that individuals with autism have the right to effective treatments that are scientifically-demonstrated to make meaningful, positive change in their lives.

We believe that it should not be so challenging for families to find accurate information about the efficacy of various autism interventions. ASAT works toward a time when:

- ★ All families will be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.
- ★ The media will educate and not confuse parents by providing accurate information and asking the right questions.
- ★ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

What It Means to Be a Sponsor:

ASAT's Sponsors indicate their support of the following tenets:

1. All treatments for individuals with autism should be guided by the best available scientific information.
2. Service providers have a responsibility to rely on science-based treatments.
3. Service providers should take steps necessary to help consumers differentiate between scientifically validated treatments and treatments that lack scientific validation.
4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
5. Objective data should be used when making clinical decisions.

Become a Sponsor Now!

These sponsorships not only provide financial support used specifically for our dissemination efforts, but also send a clear message that ASAT's vision is shared by others within the professional community.

The tasks of educating the public about scientifically-validated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of all of our sponsors.

Please visit our website to learn about the [Sponsorship Benefits](http://www.asatonline.org/direct-financial-support/) for Sustaining, Partner, Champion, Benefactor, Alliance and Patron levels: www.asatonline.org/direct-financial-support/

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7. Ann, Jim, & Carol Celiberti

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