From Tarantulas to Toilet Brushes: Understanding the Special Interest Areas of Children and Youth With Asperger Syndrome

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ABSTRACT

The purpose of this exploratory study was to evaluate the impact of special interest areas on children and youth with Asperger syndrome (AS) and their families. The research team conducted interviews about special interests with 2 girls and 21 boys with AS, ages 7 to 21, who were eligible for services under autism and enrolled in an extended school year program. The team also received written surveys from 18 parents. Strong positive relationships were found between special interests and improvements in students' social, communication, emotional, sensory, and fine motor skills. Based on these findings, the researcher created a strength-based model of AS and special interests that emphasizes the critical need for teachers to understand and value the special interests of these students and the impact on their families.

From the popular press to late night television talk show guests, the media are spellbound by the special interest areas (SIA) of individuals with Asperger syndrome (AS). In the acclaimed motion picture *Rain Man* (Guber, Morrow, Bass, & Levinson, 1988), the public encountered SIA with Raymond Babbitt's perseverative focus on Judge Wapner and the television program *The People's Court* (Billet & Edwards, 2005). In 2003, television host Oprah Winfrey (2003) invited 9-year-old Elizabeth Mule to share her expertise about tarantulas and their mating habits. Recently, *Hollywood Access* hosts interviewed Gilles Tréhin (2006), the creator of more than 200 drawings depicting the landscape, architecture, and history of *Urville*, his imaginary European city. In a program entitled "Brainman," the Discovery Channel (2006) interviewed Matt Savage, a 14-year-old professional jazz musician and composer with 3 CDs and his own trio. They also featured Stephen Wiltshire, a young British artist with phenomenal drawing gifts and photographic memory.

The families of children and youth with AS are well aware of these all-consuming special interests. Attwood (2003) stated that SIAs seem "to be a dominant characteristic, occurring in over 90% of children and adults with AS" (p. 127). SIA can include such diverse fascinations as deep-fat fryers, the passenger list of the Titanic, waist measurements (Klin, Volkmar, & Sparrow, 2000), the livery of Great Western trains (Tantam, 1991), Rommel's desert wars, paper bags (Gillberg, 1991), light and darkness (Kanner, 1973), toilet brushes (Attwood, 1998), globes and maps (Myles & Simpson, 2003), yellow pencils, oil paintings of trains (Attwood, 2003), photocopiers (Myles & Adreon, 2001), the World War II propeller plane Hawker Hurricane (J. W. Messiers, personal communication, August 20, 2006), industrial fans, elevators, dust, or shoes. Recognizing that neurotypical people may be mystified at the attraction that these interests hold for those with AS, Frith (1991) pointed out, "the interest may appear excessive, abstruse and sterile to others, but not the Asperger person" (p. 14). Frith (1991) wisely noted that the response of the neurotypical world to the SIA of an individual with AS depends largely on how acceptable the SIA feels to the observer. She observed that "a child who talks about electricity pylons all the time is more likely to be thought

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oddly fixated than one who talks about horses or football teams" (p. 239). Professionals in the autism field are conscious of these unusual passions in the lives of their students and clients. Although SIA are one of the defining characteristics of individuals with AS, they are a key area on which almost no research data exist. Parents and educators often view SIA only as annoying, socially inhibiting, even harmful activities, and the students' involvement in them as behaviors to extinguish (Attwood, 1998).

Many of the major figures in autism research have referred to SIA in those with autism or AS in their writings. Among them, Hans Asperger (1944/1991) first noted the unusual interests of his patients, observing that "a special interest enables them to achieve quite extraordinary levels of performance in a certain area" (p. 45). Attwood (1998) referred to these fascinations as "special interests" (p. 96). Myles and Simpson (2003) labeled them "obsessions" (p. 58) and divided them into "primary and secondary." Baron-Cohen called them "obsessions and compulsions" (p. 193), whereas Gillberg (1991) referred to them as "odd all-absorbing interests" (p. 140). Attwood (2003) later called them "circumscribed interests" (p. 126), and Klin et al. (2000) called them "circumscribed topics" (p. 353). Happé (1991) labeled them "fixations" (p. 239) and also noted the "poor understanding we have of obsessive behaviors and interests in Asperger syndrome" (p. 239). Furthermore, Frith (1991) observed, "The odd interests of Asperger people are a largely unexplored feature" (p. 14). Baron-Cohen (1989) wrote that whereas social relationships and communication "have received a great deal of research attention, [obsessional or stereotyped behavior] has received almost none" (p. 193). Citing multiple references, Baron-Cohen (1989) emphasized that the literature is replete with allusions to the "obsessions and compulsions" (p. 193) of children with autism. He described them specifically as "repetitive and narrow interests" (p. 194) but debated whether "such phenomena [should] be called 'obsessions' and 'compulsions'?" (p. 194).

Nevertheless, a search of key peer-reviewed autism journals, foremost publications on AS, and the Educational Resources Information Center (ERIC) and PsycINFO databases revealed few studies in which the authors focused their research on the special interests of individuals with autism or AS. Keywords used in the investigation included *special interests*, *intense interests*, *interest areas*, *obsessions*, *fixations*, *repetitive behaviors*, *special fascinations*, and *passions*, in conjunction with *Asperger syndrome*, *Asperger's disorder*, *high-functioning autism*, *autism spectrum disorder*, *autism*, and the authors *Asperger*, *Kanner*, *Wing*, *Rimland*, *Baron-Cohen*, *Digby*, *Gillberg*, *Grandin*, and *Myles*.

Among the few studies that referred to special interests was one by Kerbeshian and Burd (1986). This was a brief case study of DD, a 13-year-old boy whose special interest was pinball machines. He made meticulous drawings and built his own pinball machine. Kerbeshian and Burd used descriptive vocabulary to describe the participant's special interest, noting that DD "admitted to ritualistic and obsessive concerns such as compulsively drawing schemata for pinball machines" (p. 734). In a follow-up interview 5 years later, DD's mother noted that DD, now 18 years old, "had become obsessed with computers" (p. 734). Although Kerbeshian and Burd did not investigate special interests per se, they observed DD's interest in pinball machines and obtained limited parental input on DD's special interest–related development and behavior. They also included a table describing the AS characteristics of six individuals with "autistic-like symptomatology" who had "circumscribed interests," including "mental telepathy," "spend[ing] hours drawing elaborate diagrams," "music," "electronics and energy," and "radio programmes" (p. 733).

In 2002, the National Autistic Society (NAS) published the findings of a study they had commissioned on the role of Thomas the Tank Engine™ and related characters in the lives of young children with AS. Researchers surveyed 81 parents of children with autism and AS with the goal of exploring their "special relationship" (NAS, 2002, ¶ 1) with Thomas the Tank Engine. They found that "57% of children on the autism spectrum associate with Thomas before any other children's character" (¶ 2). They also noted that these children retained their strong interest in Thomas the Tank Engine for 2 years beyond their neurotypical siblings. About 30% of the responding parents deemed that their children had "an obsessive relationship with Thomas" (¶ 2). One parent in the study, commenting on the soothing effects of Thomas on her 2-year-old son, reported that Thomas "calms him, stops his tantrums, makes him relax. . . . Thomas has been a wholly positive influence" (¶ 12).

In explaining SIA, Attwood (1998) noted that they "dominate the person's time and conversation and the imposition of routines that must be completed" (p. 89). Describing the difference between the interests of neurotypical individuals and those with AS, Attwood further wrote, "These pursuits are often solitary, idiosyncratic" (p. 93). Piven, Harper, Palmer, and Arndt (1996) found that, in contrast to the communication and social deficits of the AS profile, such "ritualistic and repetitive behaviors" (p. 528) did not improve significantly with age. In response to those who view SIA as compulsive, however, Attwood affirmed that "the person really enjoys their [*sic*] interest and does not try to resist it" (p. 93). Tantam (1991) noted that "these self-selected leisure activities are both unusually narrow and unusually engrossing . . . pursued privately and with no eye to their social implications" (p. 159). Theorizing about the origins of the special interests of those with AS, Tantam (2000) summarized that SIA "may all be attempts to find a powerful quantitative clue to society" (p. 384).

The purpose of this study was to address the primary question, what are the origins and development of special interest areas in children and youth with AS? The secondary question was, how can SIA be integrated most effectively into school and home? For the purposes of this study, SIA were

defined as those passions that capture the mind, heart, time, and attention of individuals with AS, providing the lens through which they view the world.

Method

Researchers

The research team consisted of the author and nine graduate students in Project PASS (Preparing Autism Specialists for Schools) in the special education department of the University of Oregon. The researchers included special education professionals, a speech–language pathologist, and several mothers of children with autism spectrum disorders. Under the instructor's guidance, the students enrolled three terms each year in an optional qualitative autism research class designed to teach them to identify a research question, design a study, obtain university and school district Committee for the Protection of Human Subjects/Institutional Review Board approval, prepare a literature review, organize and conduct action research, analyze the data, and build evidence-based theories.

Participants and Setting

District individualized education program (IEP) teams referred the children and youth who took part in this study to two extended school year (ESY) programs for students with AS. Both ESY programs took place during the summer of 2005 at two different school sites in the Pacific Northwest, drawing students from a number of local districts. Five of those districts approved our request to send letters of invitation to the parents or guardians of students enrolled in the ESY programs. All students had IEPs, were eligible for special education services under the category of autism, and received services under the 1990 Individuals with Disabilities Education Act (IDEA).

Thirty parents and guardians of students with AS receiving ESY services received letters inviting their children to participate in our study. Of those, 26 parents agreed, representing a response rate of 88%. Of those children and youth who received parental permission to participate, 24 agreed to be interviewed—a response rate of 92%. Twenty-one participants were male and three were female. Twenty-two children and youth were European American, and two were Native American/Alaskan. Participants were between 7 and 21 years of age. After completing the interviews, one of the students was deemed ineligible to participate in the study, as she did not have a diagnosis of AS.

Letters were also sent to parents and guardians of all 30 ESY students whose school districts approved the study, inviting them to respond to a written survey, whether they gave permission for their children and youth to participate in the study or not. Eighteen parents returned their surveys, a response rate of 60%. Fifteen of the 18 parents had completed some college education or held college degrees. Ten parents annually earned $40,000 or more. Fifteen parents identified as European American, two identified as Native American/Alaskan, and one declined to disclose. Parents reported spending between $100 and $5,000 annually on their child's SIA, including expenses such as (a) related clothing, (b) personal items, (c) toys or objects, (d) books, (e) software, (f) supplies, (g) classes, (h) outings, and (i) overnight trips.

Instruments

Two instruments were designed as data collection tools. The first was a 14-item set of interview questions, with clarifying questions to use as needed. Clarifying questions also served as alternative wording for older participants (see Appendix). The second instrument was a 40-item written survey for caregivers. Parents and guardians had the option of requesting an anonymous telephone interview with the instructor or completing the survey independently and returning it through the mail. One requested the interview; the remainder completed the written survey. School district personnel mailed surveys to students' homes, and parents and guardians returned them in stamped envelopes with no identifying marks.

Themes reflected in the survey included (a) the developmental history of the student's special interest, (b) a family history of similar interests, (c) the amount of time that the student spent daily and weekly in pursuing the interest, (d) the impact of the interest on siblings and family life, (e) ways in which parents and guardians supported their children's special interest, and (f) caregivers' attitudes and beliefs about their children's special interests.

Procedure

Interviews were held at each ESY school site over several days. Researchers worked in pairs: one researcher was assigned to conduct the interview, the other was responsible for monitoring time limits, preparing forms, running audio equipment, and taking field notes. Team members rotated roles across interviews. Individual interviews were limited to 20–25 min in order to conform with school district administrators' requirements. With participants' assent, interviews were audio recorded. All participants agreed to be recorded. The instructor supervised all interviews and was available to support both graduate students and participants. All interviews were completed as planned, and participants were escorted back to their classrooms. An ice cream party was held for the entire ESY program and staff when the interviews were completed.

Data Analysis

The research team used a sequence of tasks to guide the data analysis process: (a) transcribing all interviews, (b) developing code themes, (c) coding the transcripts, (d) grouping the

coded text into subcodes, (e) organizing subcoded text into brief paraphrased statements on each major theme, (f) searching parent surveys to find relevant citations, (g) identifying supporting quotations of children and youth to add to memos, and (h) identifying theories that emerged from the evidence.

Transcription and Coding. More than 400 hours were spent transcribing the interviews, producing a total of 226 typed pages of transcribed interview text. Transcribers replayed interviews on tape recorders and entered them in computer files. Interview tapes and audio recorders were checked out from the instructor, and completed transcripts were sent by e-mail attachment to the instructor. Interviews to be transcribed were assigned to teams of two researchers, each of whom had participated in the original interview. Researchers transcribed the interviews exactly as they were given, making no grammatical corrections or interpretations of what the participants intended. Transcribers phonetically transcribed unusual or difficult sounds in an effort to maintain potential implications for data coding and analysis of intonation, pitch, emotion, vocabulary, fatigue, humor, or echolalia.

As the transcription teams worked, they noted coding themes that emerged repeatedly in the interviews, such as special interest areas; strategies for learning about and improving interest area skills; relationships with parents, siblings, and friends or acquaintances; self-image; feelings about and experiences at school; career plans; and unusual vocabulary or speech patterns, such as a "little professor" (Gillberg, 1991, p. 137). The team met weekly during the transcription process to check the quality of the transcriptions and to discuss emerging coding themes.

When the transcriptions were completed, a series of codes was developed to apply to the transcribed texts. After checking interrater reliability in three practice rounds of interview coding, teams of two coders were assigned to code interviews on which they had never worked. Each team combed meticulously through their assigned interview transcripts, using multiple colored highlighters, computer-applied color, and handwritten margin notes and symbols to designate words, phrases, and passages relevant to each code or new code they created. These coded portions were then entered exactly as transcribed into the computer under the specific code, with page and line numbers referenced.

Next, the team identified 75 subthemes, such as specific types of strategies to learn about the SIA, including reading, researching online or at the library, talking to experts, exchanging e-mail with professionals in the field, looking up Web sites, taking classes, and watching television programs or movies relevant to the interest, and assigned the SIA to these subthemes. Several hundred strips of paper with interview excerpts were affixed under each appropriate subtheme on 12 large sheets of paper on the walls. The end result was a huge visual representation of our coded data that immediately revealed which of our subthemes were well supported by the evidence and which were not.

The final step in preparing the coded data was to organize them in related groups. Several subthemes emerged. For example, subthemes such as anger, sadness, depression, calming, stress, joy, happiness, insecurity, and security were identified as methods of self-calming when feeling negative emotions and the impact of the SIA on self-image.

Writing Memos. Next, teams of two writers took these sets of related, subcoded texts and paraphrased the essential ideas from the data. After items were culled, each writing team exchanged their work with another team. A team that had not worked with the data set before studied the evidence to ensure that the paraphrased version reflected the original transcript. Next, writing teams introduced more than 100 supporting quotes from parents, children, and youth into their memos. Once again, information was exchanged, and the quotes were studied for their relevance and appropriate placement. Disagreements were discussed until consensus was reached.

Concurrent with this activity, interview field notes and parent surveys were analyzed. One team studied field notes for behaviors that would not be apparent from the recorded interview, such as furrowed brow, hand flapping, body posture, foot tapping, blushing, unusual breathing, or playing with interview items on the table. The team discussed these observations and how they affected, supported, or contradicted the verbal content of the interviews.

Validity Criteria. Whittemore, Chase, and Mandle's (2001) validity model was used for this primarily qualitative study. Altheide and Johnson (as cited in Whittemore et al., 2001) defined *reliability* as "the stability of findings" (p. 523), and *validity* as "the truthfulness of the findings" (p. 527). In the context of Whittemore et al.'s (2001) review of the tension between researchers' perspectives on qualitative and quantitative research, the research team sought findings that were both stable and truthful.

Of particular importance was Whittemore et al.'s (2001) emphasis on triangulation—the need to demonstrate the credibility of one's evidence through multiple sources. Because the school districts' ethics commissions approved only one round of interviews with participants, we looked to other data-gathering methods as the second and third elements of triangulation. In addition to the interviews, the team determined that the second source would be the extensive handwritten field notes taken throughout the interviews by the second member of each interview team. The third source was data gleaned from the 18 written surveys completed by parents and guardians of participants. Through these three sources of evidence, all providing solid audit trails, the research team was able to continuously verify the reliability and validity of the findings. Furthermore, a visual trail of the research via digital photographs was created during every phase of the analysis process.

Seventeen of Whittemore et al.'s (2001) "techniques for demonstrating validity" (p. 533) were used in this study.

Table 1 lists these techniques and describes how the team applied them. Throughout each step of the research process, team members exchanged their work to critique the accuracy, quality, integrity, reliability, and validity of each person's work. No evidence-based conclusions were finalized until team members agreed that the conclusions accurately represented the data to the best of our ability.

Results

The range of findings was vast. SIA-related themes were grouped into the following categories: content, self-image, social skills, emotions, communication, fine-motor and sensory skills, parents, and skill development. Using these themes, three principal theories concerning the participating children and youth with AS emerged.

Content

Among our participants, all of whom enthusiastically talked at length about their SIA, we identified 22 special interests, which were categorized into eight interest themes. These included classic SIA as well as unusual ones. The themes were transportation, music, animals, sports, video games, motion pictures, woodworking, and art. See Table 2 for a list of the SIA of all participants. The participants noted that they saw nothing unusual or extraordinary about their SIA.

During the interviews, students demonstrated extensive professional knowledge of their SIA far beyond what would be expected at their ages. In their survey responses, parents such as Brock's mother noted that her son enjoyed "sending and receiving e-mail from experts [and] talking with family friends knowledgeable in aviation." Four parents reported that their children liked to visit local experts in their respective SIA.

Although our female sample was small ($n = 2$), the participants' SIA affirmed Cohen's (2003) research on the interests of girls with AS, in which she found that the most popular interests among her participants were art—primarily drawing and cartooning—and animals. The interests of the two girls in our study were manga and horses. Sarah, one of the two girls in our study, firmly stated, "I'm an animal person. [People] can sense that I am an animal person."

Some SIA were unacceptable, either because parents considered them socially inappropriate or because they considered the amount of time and energy invested in the SIA inappropriate, even if the SIA was otherwise socially acceptable to them. One parent affirmed that in particular, "the *intensity* [of his SIA] is not acceptable." Justin's grandmother wrote, "He obsesses and can't take himself away from the games and we end up having to confront him. I can't handle it." She further revealed her anguish, adding, "He rambles on and on about [video games] or things regarding himself . . . no interest shown in others. This kid is going to fail in every way in this world, unless he gets help."

Some parents expressed particular concerns about their children's involvement in violent video games. Lee's mother reflected the tension echoed by many parents in our survey when she wrote, "I have tried to limit his access and time on video games. It was always a fight and nothing gained." Worried about the impact of her grandson's special interest in video games, Justin's grandmother stated, "He works for money basically to buy more games. These are $50 games. *Not* of my choosing." She further confided, "My grandson needs someone to help him meet reality head on. What will he do in the future?"

Self-Image and Social Skills

As we interviewed each participant, it became clear that their SIA were inextricably entwined with their self-images. Although their self-images apart from their SIA were strongly negative, we found that when they were involved in activities related to their SIA, they felt more positive about themselves. Participants demonstrated expertise in their SIA, control over their knowledge and involvement in their SIA, and increased self-confidence. One participant, Ryan, confided, "I think I've got a *lot* more understanding on how things work than most people. I've got a corner in the back of my brain that allows me to perfectly simulate almost anything." Steve told us, "I'm the main customer at a place called Hollywood Video. I am a movie *whiz*!"

Nevertheless, participants were reluctant to tell others about their SIA due to fear of rejection from their peers. Participants also noted that they were frustrated at being misunderstood by others. Their SIA were often seen as socially unacceptable, and their peers lacked understanding and interest in participants' SIA. Charlie clarified, "I also make dragons, not just dinosaurs. Everyone needs to know what they are . . . dragons, dragons, *dragons*!" Similarly, Brock admitted, "I just wish they'd think planes were cool."

One student revealed his feelings of peer rejection, as well as his desire to be the expert, when he told one interviewer, "I wish [kids at school] would accept [my interest] and, uh, not always pretend to throw up about it. . . . I just wish they knew as much about it as I do, maybe even . . . no, maybe not even more." Participants clearly wanted to be recognized as experts and be accepted by their peers. As Charlie said, "Well, I first like *tell* 'em I'm talented, but then I like wanna *prove*, I mean *PROVE*, that I can do it." One participant confidently told us, "Yeah . . . well . . . apparently, like, when I make something very good, then they'll be impressed."

Many participants, such as Brock, revealed their social savoir faire in their cautious dealings with peers, testing the waters before revealing their SIA. "First, I usually don't talk about it, . . . and if I have a really good friend . . . they might come over to my house, and then they'll see all these planes around, and they'll tell me that 'planes are a really cool thing' . . . and then I'll know." Justin told us, "Video games

TABLE 1. Whittemore et al.'s (2001) Validity Demonstration Techniques Used in This Study

Technique	Application of technique in study
Design considerations	
Developing a self-conscious research design	We discussed our personal biases, theories, and roles in the field of ASD in depth.
Employing triangulation	We identified interviews, field notes, and parent survey data as our three elements of triangulation.
Giving voice	One of our principal reasons for conducting the study was to give voice to children and youth with AS about the importance of their SIA in their lives.
Expressing issues of the oppressed group	We identified the participants as oppressed in that they and their SIA are frequently misunderstood and undervalued.
Data generation	
Articulating data collection decisions	We worked together to plan how data collection would be conducted and to be certain that data gathering plans and goals were clearly stated.
Providing verbatim transcription	Transcription teams were committed to high levels of accuracy, detail, and quality in their transcription of the interview tapes.
Analysis	
Articulating data analysis decisions	We worked together to plan for analysis of the data and to be certain that data analysis techniques and implications were clearly stated.
Testing hypotheses in data analysis	We discussed every hypothesis and searched for multiple data sources before confirming data-based theories.
Drawing data reduction tables	We did not draw tables per se but spent time discussing which minor subthemes to eliminate due to lack of frequency of appearance among interviews.
Exploring rival explanations	We discussed alternative explanations for the range of participants' behaviors and verbal statements such as fatigue, difficulties at home, the challenge of being interviewed by strangers, interview anxiety, and so on.
Performing a literature review	We performed a thorough literature review using more than 21 descriptors in ERIC, PsycINFO, and other sources.
Memoing	Memoing Memos were written concerning each major theme group and critiqued by at least two other teams until team members agreed on the memo's content.
Writing an interim report	We wrote interim reports on each major theme that were integrated into data and findings. These reports were used to discuss and test theories.
Providing an audit trail	Our audit trail included audio-recorded interviews, field notes, handwritten parent surveys, electronic and hard copies of all interview transcripts, transcript coding, memos, audiotaped discussions on all aspects of the research project, and study validity and reliability.
Providing evidence that supports interpretations	Our interviews, field notes, parent surveys, multilayered coding, and frequent, thorough discussions all supported our interpretations.
Acknowledging the researcher perspective	We recognized and acknowledged to the university and school district institutional review boards, and in our presentations of findings, that we were special education professionals and that several of our members were mothers of children with ASD.
Providing extensive descriptions	We took more than 50 typed pages of field notes observing children and youth's body language, posture, attitudes, movement, emotion, fatigue, blushing, self-stimulating behaviors, facial expressions, tone and pitch of voice, and interaction with interviewers and the interview environment.

Note. ASD = autism spectrum disorders; AS = Asperger syndrome; SIA = special interest areas.

TABLE 2. Overview of Participants' Primary Special Interest Areas

General theme	Interest area
Transportation	Airplanes
	Cars
	Trains
	Trucks
Music	Composing
	Drumming
	Rap music
	Saxophone
Animals	Frogs
	Goats
	Horses
Sports	Swimming
Video games	Role-playing games (RPGs)
Motion pictures	Disney movies
	Star Wars
	Vampire movies
Woodworking	
Art	Anime
	Cartooning
	Manga
	Sculpting

Note. Although $N = 23$ in our study, the number of interests does not total 23 because several participants shared the same special interest.

used to be at the top of my list. Now I always put girls at the top of my list. If it's a girl, I'll hang back, observe, see what kinda things *she* likes, and I'll move in slow and steady. One could say that I like to buy lunch for pretty girls." Charlie shared with us his strategy concerning his intricate clay dinosaur creations: "Well I don't tell 'em, but, like, people just start lookin' at 'em." One participant shared his strategy: "I'd talk to them about what their interests are first."

We also found that participants often used video games or other popular interests as a social bridge, even if they themselves were not participating in them as their SIA. We labeled this practice the *masking of special interests*, because we found that participants used this technique to hide perceived socially unacceptable SIA from their peers while still interacting with them. For example, seven male participants immediately identified video games as their SIA. As we interviewed them, however, we learned that they played video games to fit in with peers because peers rejected their true SIA. For example, Tom said that video games were his SIA, but later acknowledged his passion for woodworking. Peter revealed his masking process when he told us, "Uh, I'm a gamer, uh, but my favorite video game, the only one I am actually good at, would be *First Person Shooters*. . . . But the truth is, I like frogs . . . frogs, frogs, frogs, frogs**!** I have, like, so many frogs at both my mom and dad's houses, and I'm not going to ever sell them or give them away or stuff like that. If I was going to sell them, which I'm not, I'd be rich! Really, really *rich*!"

Owen was willing to be flexible in talking with peers, saying, "If they don't look interested I change the subject. I say, 'Hey, I can change my voice.' " Steve, however, had learned self-preservation by backing off when teased by peers: "I don't really wish other people would know about it." Charlie confided, "They wouldn't, like, care anyway." Peter revealed, "Oh, I don't usually like, tell a lot, not until . . . I know that they won't start getting on me, just because I like video games."

Emotions

Participants shared that they felt positive emotions, including enthusiasm, pride, and happiness, when actively engaged in their SIA. Danny could barely contain his joy in repeatedly telling the interviewers, "I was born to like . . . Walt Disney. Walt Disney is my life. Disney has been my most happiest hope in my whole life." Nate, whose SIA was musical composition, proudly told the interviewers, "My parents think I'm an unbelievable, amazing drummer." Convinced of a successful future in composing music scores for films, Nate confidently declared, "The reason I wanna move back there [to Hollywood] is, I wanna be a composer and . . . just take over John Williams' job, get into that job and compose *Harry Potter*, *The Terminal* . . . just, before I do that, I have to learn the notes." Nate described how the music made him feel: "I like composing music for movies so that I have a good feeling. . . . I like feeling sad, happy, scared, sneaky."

In the face of negative emotions, participants had learned to focus on their SIA, actively or in their minds, to help them cope. SIA helped them to self-regulate stress, anxiety, and frustration and to calm themselves. As Sarah said, "I wish that other people, especially my parents, knew that whenever I'm around horses, I don't think about anything else . . . like if I was stressed about one thing, and I went to see a horse or get on a horse, that thing I was stressed about, I wouldn't be stressed about anymore." Owen shared what he wished others understood about the saxophone: "It just gives you a whole new feeling that you might have never felt before. Music is so relaxing and it just opens up your spirit, I just suppose you could say."

Communication and Self-Regulation

As we interviewed participants and later listened to audiotapes, we noticed distinct speech patterns that changed when participants shifted from any topic to talking about their SIA. Their affect and animation expanded, and some participants who had shown flat affects in the pre-interview conversation

began to show significantly more enthusiasm and emotion when asked about their SIA. In some participants, we noted that their intelligibility increased markedly, and the sophistication of their vocabulary, word order, and syntax improved considerably. Responses also increased in complexity. For example, when responding to general questions, Charlie repeatedly gave answers such as "Uh, I don't think so, just, whatever," consisting of simple one- or two-syllable words with no clear content or syntax. When asked about his favorite thing to play with, however, his speech pattern changed instantly as he confidently replied, "My *favorite* is a Yu-Gi-Oh!™ card that combines with three Blue-Eyed White Dragons, and due to polymerization it forms those three into a three-headed dragon." Our team also observed improvement in body language—particularly an increase in eye contact and expressive gestures that accompanied speech. Furthermore, we noticed a remarkable decrease in self-stimulation, distraction, and body movement in and around the table and the participants' chairs.

Fine-Motor and Sensory Skills

Although children and youth typically have acknowledged difficulties in tying shoelaces, fastening buttons, and handwriting (Attwood, 1998; Myles & Simpson, 2003; Smith, 2000), our participants spoke not only of their advanced fine-motor skills but of extreme perseverance and patience with the fine-motor skills that their SIA required. For example, participants related drawing, building, sculpting, creating models, playing keyboards, using video controllers, and playing musical instruments.

Individuals with AS are often severely challenged by intense stimuli to their senses, including tactile, auditory, and olfactory (Myles, Tapscott-Cook, Miller, & Rinner, 2002). Yet despite these sensory challenges, our participants persevered for hours at a time in their interactions with model airplane glue, modeling clay, horse manure, goat odors, sawdust, sweat, sticky or dirty hands, and the bright lights, rapid movements, and loud, startling sounds of video games. For example, despite the many aversive stimuli found at a 4-H fair, Owen shared, "I also like, uh, really like, um, showing my goats in 4-H at fair . . . and hanging out with my goats." Sarah, whose SIA was horses, also loved animals and farm life, telling us "I would like to kinda go to like a farming kinda place where I could work with all sorts of animals, like sheep and, probably not cows . . . like horses and goats and all that. . . . That way I'll be around animals and horses." Brock, passionate about aviation, told researchers about a recent trip to attend an air fair in Oshkosh, Wisconsin. He told researchers that the "T-6 [aircraft] was really loud. . . . There were some jets, some aerobatic [aviation] teams, a lot of flight simulators . . . a lotta oil." In this list, Brock indicated the many sensory stimuli that he had experienced and withstood, including challenges to auditory, visual, vestibular, tactile, and olfactory senses.

Parents

From our parent survey data, we learned that parents saw the purpose of their child's SIA as having fun, relaxing, avoiding doing another task, avoiding thinking about something else, self-calming, and reducing stress or anxiety. One parent shared that her son "uses these games as an escape." A mother observed that her son used his SIA to "self-comfort, [and when] trying to fall asleep." One parent shared that "it is important to have interests that are positive." Nearly all the parents surveyed correctly identified their children's SIA. Most participating children and youth reported that their interactions with their parents concerning their SIA were positive.

Parents' primary concerns regarding their children's SIA were that they were socially unacceptable, not age appropriate, or would not lead to college or careers. A grandmother lamented "once he is '*in*' a game, there is no further participation with life in general. . . . He rambles on and on about what he cares about, or things [about] himself. . . . No interest shown in others." One mother shared that her son's SIA "keeps him from learning new possibilities." Another boy's mother also expressed her concern for his future: "Can he really do this as a career?" Sixteen of the 18 respondent parents said that they regularly interpreted their children's SIA for family, friends, and teachers, explaining why their children were so involved in their SIA. Fourteen parents stated that their children's SIA had a positive impact on their families.

Parents expressed a wide range of emotions concerning their children's SIA. These included the five most common positive feelings in our survey data: pride, humor, fascination, pleasure, and enthusiasm. For example, Brock's mother stated, "My son inspires my respect and admiration for all he knows and his amazing brain." Marcus' mother affirmed, "It's part of what makes him special!" Justin's grandmother wrote, "I'm glad to see if Justin has an interest he can go far with. If he chose a scientific study, he could be a genius." Many parents also expressed appreciation for their children's character. One parent affirmed, "I love the fact that even though he is an Asperger's kid, he is very sweet, kind, gentle, and affectionate. . . . He has a gentle soul, even when he is angry or upset, and he is very loving to us." One boy's parent wrote proudly, "I love that he is loving and caring. I love that he has a pleasant disposition. I love that he likes to spend time with us. I love his innocence. I love his lack of guile. There is so much to love about him!" A mother emphasized her son's "enthusiasm for life, his innocence, his willingness to help, kindness to others."

Parents also expressed negative emotions about their children's SIA. The three most common were boredom, frustration, and embarrassment. Justin's grandmother expressed her weariness with her grandson's SIA when she wrote simply, "This world is ALL ABOUT *JUSTIN*!" One parent expressed her frustration, writing "It's tiring for others to listen to [him talk about his SIA] after a while; it's limiting for him, too." Another parent agreed, "It's obsessive and gets old."

Justin's grandmother divulged, "I believe [my grandson] is completely unaware of how different he is from the average 17-year-old. I love him, but I dislike how this family drama around his video games is playing out."

Some children and youth expressed frustration with their parents. Peter confided, "My dad . . . did not really accept that I am, um, a gamer." When asked what he thought his parents thought his SIA was, one boy replied, "I don't think they've really got a clue. They'd probably think the video games, 'cause they're always tellin' me to get off my butt and go do somethin."

Other participants recognized the support that their parents offered them. Will confided, "Well, yeah, I think they *do* know I'm . . . good at art." Tom, whose SIA was woodworking, told us, "I made a table with my dad." Peter proudly told us, "my dad said I had a real, um, hand–eye coordination because I could, um, look at the screen and know what I'm doing here."

Parents described the support they offered: "He has a special area set up in the garage for his interests." One mother wrote, "I am willing to do whatever he needs." Another told of "researching the questions he asks with him." A mother wrote that "his dad often plays PS2 with him."

Skill Development

Participants expressed strong feelings about the interplay of school and their SIA. Tom showed how his woodworking interest could intersect with school when he proudly told researchers, "I built like 12 projects last year in high school." One parent told of her plans "to set him up in [drawing] classes in a few years." Some parents noticed a difference in how their children performed when engaged in their SIA in contrast with their non–SIA-related tasks and activities. Nate's mother shared, "It makes us feel good to see that he has a strong interest in [music]. He has lots of anxiety, and this area shows a light at the end of the tunnel." One parent wrote that her son's SIA "gives him an outlet. . . . He is very happy, and it reduces the negative interactions in the house."

Half of our participants reported that reading books was their preferred strategy for learning about their SIA. Will told us, "I always like going to the library; they have really good books." When asked if he learned about Disney facts from watching movies, Nate replied, "I even find them out in books, too. I have a *Disney A to Z* book that tells me everything about Disney." Many participants told us they also read about their SIA online. Sarah said, "I like to read books a lot and learn a lot about other, different breeds of horses. Or, I like to look on the Internet and books, magazines, and all that." Tom asked us, "Do you know Arizona is supposed to have thunderstorms coming up soon, some time this week actually they are supposed to have thunderstorms happening there. I read . . . I saw it on Netscape."

Our participants recognized the strategies they used to learn and saw their involvement in their SIA as a method for learning other skills, too. As Ryan shared, "People that play too much games . . . I know I play too much games . . . but . . . I have two reasons why: one, 'cause I learn how to do some things through games that . . . in normal life I can't begin to formally learn . . . and two, I like to escape to a fantasy reality."

As Asperger (1944/1991) observed, "We can see in the autistic person, far more clearly than with any normal child, a predestination for a particular profession from earliest youth. A particular line of work often grows naturally out of their special abilities" (p. 88). When asked about their plans after high school, all but one of our participants had clear ideas about college and career, linking their present SIA to dreams of future professions. They also saw their SIA as helping them achieve their future goals. Soon after submitting her survey, Nate's mother sought out the author to explain that her son "doesn't watch DVDs for the movies, but watches all the 'behind the scenes' segments of DVDs. Actually, he knows them by heart. They help him feel like a composer, and he thinks he learns all the inside tricks. He says, 'I figure I'm saving time in the future.'?" Nate himself told researchers, "I just have to work at my hardest to be a composer and go, compose music."

Further Data Analysis

Our research yielded a considerable amount of data, the full analysis of which has not yet been completed. We have much more to learn, especially from some areas of our study, such as the oral and body language samples, the behaviors that were noted in the researchers' field notes, and the participants' handwriting samples visible in their consent forms. We have only begun to analyze the parent surveys in depth, and we anticipate learning much more about parents' feelings, concerns, involvement in their children's SIA, and the impact of the SIA on siblings, daily structure, family leisure time, and family relationships.

Theories About SIA

Although some research studies end with the presentation of the findings, our team agreed that we wanted to speak for our participants and their parents by going beyond our findings to construct theories based on our evidence. We constructed theories concerning the fusion of special interests with the core self-image, the integration of SIA into the curriculum, and the SIA strength-based model.

Fusion of SIA with Core Self-Image. Children and youth with AS define themselves by their SIA. After their family, their SIA are the most important to them. Indeed, they feel they *are* their SIA. Clearly, SIA serve a critical purpose for children and youth with AS; they are vital to their well-being. SIA are not merely a hobby or a leisure activity, and children and youth with AS do not want them to be taken

lightly. In their special interests, they find stability—a way to make sense of the world. In their SIA, these children and youth acquire clear focus, a way to organize the world, a social approach, and a way in which to interpret life.

When, as parents, teachers, and peers, we deny a child or youth the importance of his or her SIA, we are literally denying the student his or her identity. If children and youth with AS cannot feel safe and supported in openly revealing their SIA at school, we are forcing them to leave *themselves* at home. As the author's son once told her, "Airplanes are *who I am*."

Integration of SIA into the Curriculum. Because SIA are such a vital element in the self-image and motivation of children and youth with AS, it is imperative that they be welcomed and encouraged at school. From our data, we learned how deeply participants and parents feel about respecting their insights concerning making room for SIA at school. We also learned how strongly the participants wanted teachers to incorporate their preferred methods of gathering information—particularly reading—into the curriculum. We cannot afford to ignore our students' SIA or withhold engagement with their SIA as punishment for misbehavior. With little additional effort, SIA can be integrated into all core academic areas, including English, reading, writing, spelling, math, science, speech, and history (see Note). Teachers who integrate SIA into academic work may also see the generalization of motivation and skills in other academic areas. Most important, encouraging students to merge their SIA with their academic work may provide the perfect forum for them to demonstrate their true levels of ability in academic assignments. SIA are the tool par excellence for students with AS in the classroom. Table 3 outlines an example of academic assignments for a middle school student whose SIA is World War I biplanes.

Students can also benefit from simplified versions of their SIA to deal with negative emotions, reduce anxiety, and calm themselves in stressful situations. Students identify with their SIA; therefore, a favorite small airplane, stuffed frog, photograph of a prized goat, sheet music of a revered composer, cover from a preferred DVD or videotape, or recent animé drawing may help a child in self-calming and reducing disruptive, anxiety-driven self-stimulation or other unwanted behaviors. We must see SIA for the gold mine they are in helping our students progress toward their academic, social, emotional, communication, and behavioral goals.

Unquestionably, making the shift to inviting SIA into the academic arena requires effort on the part of educators and parents. The educational community must be willing to think creatively in order to find ways in which to insert the SIA effectively and appropriately into the curriculum. As educators, we must be flexible, looking beyond the strict limits of the lesson plans and assignments, asking ourselves, "Is it our goal that Samantha write about summer vacation, or is it our goal that she learn to write, even if she chooses to write about carnivorous plants?" Teachers must partner with parents, seeking their input on their children's SIA, their ideas for how to integrate the SIA into the curriculum, and even their practical help in modifying assignments to incorporate the SIA. Finally, educators and parents must embrace SIA as a means to an end—not an end in themselves.

SIA Strength-Based Model. Although our team recognized the acknowledged traditional deficits of those with AS, a parallel, strength-based model has emerged from our research into SIA. We consistently observed that deficits *diminished* when children and youth engaged in their SIA. For each of the recognized deficits, including language and body language, social communication, emotions, sensory, and fine motor skills, the SIA strength-based model includes a positive parallel to the traditional deficit model. As stated earlier, participants' language improved consistently when they spoke of their SIA. Their body language also improved, as demonstrated in increased eye contact and gestures, whereas self-stimulation and distraction decreased.

Furthermore, participants' social communication increased in fluidity and fluency, and they became noticeably more at ease. They demonstrated heightened social sensitivity in being able to recognize peers' subtle social cues when their SIA were discussed. They were also able to anticipate when and with whom they could safely introduce the topic of

TABLE 3. Example of the Integration of a Special Interest Area into Core Middle School Curriculum: World War I Biplanes

Academic area	Biplane-integrated assignments
Reading	Read *Biggles Over France* (one of a classic adventure series about World War I pilot Biggles and his biplane)
Writing	Research and write a paper on the Red Baron
Spelling	Learn aircraft parts vocabulary
History	Study the impact of aviation on World War I
Speech	Present the life history of Wilbur and Orville Wright
Math	Calculate biplane fuel consumption
Science	Study theory of aerodynamics
Art	Design and build a balsa wood model of the Sopwith Camel
Internet skills	Learn to surf appropriate biplane and biplane history Web sites and positive aviation games, and correspond with pilots and biplane experts

their SIA. Although typically negative about themselves in many aspects of their lives, they spoke positively about themselves in relation to their SIA. Intense sensory stimuli, usually a challenge for children and youth with AS, became tolerable as participants persevered with their SIA in spite of heightened negative sensory stimulation. We discovered similar strengths when participants who were challenged in some fine motor skills were able to perform SIA-related tasks that required sophisticated fine motor abilities.

The general understanding of the AS profile is entrenched with deficits. Although these deficits are critical to a thorough understanding of AS, they do not present the entire profile. Accustomed to defining AS by a deficit model, we must also define AS by a strength-based model. SIA are a strength in themselves, but if we look at the classic deficits of AS through the lens of SIA, we see that SIA affect those deficits significantly, transforming them into strengths. This alone should strengthen our resolve to embrace the SIA of the children and youth we serve.

Discussion

Strengths

Our study had several strengths that made our research and analysis more effective. We had a relatively large sample from a variety of school districts. We had relatively high response rates from parents and participants. We enjoyed quality interactions with our participants, who patiently endured being questioned by researchers they had never met. We were able to hold consistently to our interview structure, and all interviews were completed. Our team generated a large amount of data and worked together to ensure interrater reliability and the validity and reliability of our data analysis and interpretation.

Limitations

Nevertheless, the study also had limitations. The school districts' institutional review boards limited the length and number of interviews we could hold with the participants; it is possible that the research project would have been strengthened by a second round of interviews to ask follow-up questions and to observe participants' social, emotional, and communication skills with interviewers with whom they had previously worked. Given the natural fatigue that many participants experienced as the interviews progressed, however, it may not be effective to extend interview length or to conduct a second round with the participants.

Although we had a large overall sample, our female sample was small. Moreover, the inclusion of more participants from diverse ethnic and socioeconomic backgrounds might have affected the results of this study.

Implications for Practice

To know a child or youth with AS is to know his or her special interest area. SIA are serious, core passions, and we cannot truly know a student with AS without knowing his or her SIA. This means that as educators, we must make a radical shift in learning and teaching. We cannot just shy away from SIA that make us uncomfortable or are unfamiliar to us, such as frogs, animé, or fantasy dragons. SIA are powerful tools, and we must harness their power to become more effective educators and parents.

Recommendations for Future Research

As we progressed throughout our study, we discussed other studies that would have the potential to contribute significant findings to the study of SIA. We would like to replicate the study in a different setting, with a different population, such as home-schooled students. We would like to design a study to place more emphasis on learning about the origins of SIA. Also, we need more studies about the SIA of girls with AS, and how the manifestation of their SIA may differ from that of their male peers. We also need more expressive writing samples from children and youth about their SIA. Furthermore, we would like to compare the expressive writing and the handwriting of children and youth with AS when writing about SIA versus non-SIA topics. Finally, there is a need for neurological research comparing functional magnetic resonance images conducted while participants are actively engaged in their SIA versus in non-SIA activities.

Conclusion

As a field, we have too long viewed SIA as the always quirky, sometimes delightful trailing shadow of AS. It is time to take special interests seriously. In the lives of children and youth with AS, SIA hold the promise not only of increasing individual progress and quality of life in childhood but of meaningful, successful careers in the future. As Asperger (1944/1991) so eloquently affirmed,

> Able autistic individuals can rise to eminent positions and perform with such outstanding success that one may even conclude that only such people are capable of certain achievements. It is as if they had compensatory abilities to counterbalance their deficiencies. Their unswerving determination and penetrating intellectual powers, part of their spontaneous and original mental activity, their narrowness and single-mindedness, as manifested in their special interests, can be immensely valuable and can lead to outstanding achievements in their chosen areas. (p. 88) ■

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NOTE

It is not our intention that a student's special interest be integrated into every academic assignment, or that a student should never be required to complete a traditional assignment as originally designed by the teacher. Rather, the integration of SIA can be used to motivate a student to learn skills and to complete assignments.

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(see Appendix on next page)

Appendix
Special Interest Area Research Study—Interview Questions for Children and Youth

1. What is your favorite thing in the whole world?

Prompts, if needed, or wording for older students:

- What do you like to do best?
- What is your favorite thing to do?

2. What do your parents think your favorite thing is?
3. How long has (*answer to Question 1*) been your favorite thing?
4. Do you remember how you started liking (*answer to Question 1*)?

Prompt, if needed:

- Tell us (more) about that.

5. When do you like to think about (*answer to Question 1*)?
6. What do you like to tell people you meet for the first time about (*answer to Question 1*)?
7. What do you wish that other people knew about (*answer to Question 1*)?
8. What is your favorite way to learn about (*answer to Question 1*)?

Prompts, if needed:

- Reading books
- Going to the library
- Doing Internet activities
- Watching television
- Watching videotapes or DVDs
- Asking other people
- Asking experts

9. How much time do you spend each day thinking about (*answer to Question 1*)?

Prompts, if needed:

- 1 hour
- 2 hours
- 3 hours
- More than 3 hours
- A little bit of the time
- Some of the time
- Most of the time

10. Do you ever talk to kids about (*answer to Question 1*)?

Prompt, for high school students:

- Peers

11. What do you want to be when you grow up?

Prompt, for middle and high school students:

- What do you want to be after you finish high school?

12. Is there anything else you want to tell us about (*answer to Question 1*)?
13. Is there anything else you want to tell us about you?

If yes, prompt, if needed:

- Please tell us more.