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Experiences of Parents Who Homeschool Their Children With Autism Spectrum Disorders

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Abstract

Teachers may be inadequately prepared for the increasing number of students being identified with autism spectrum disorders (ASD), as students with ASD may not respond to traditional methods of instruction. Some parents of children with ASD are concerned with educational programming available through public school systems and are turning to homeschooling. Ten parents from nine families participated in this qualitative study to share their experiences, opinions, and perceptions of homeschooling as compared to instruction in public school settings. Four themes emerged from the data analysis, along with one overarching theme. The 10 parents who homeschool their children with ASD believe they have found a treatment plan that works, and their perception has been that the school has been either (a) not willing and/or (b) unable to provide effective programming. An unexpected finding was that homeschooling goals and interventions varied across the families.

Keywords

autism, homeschooling

In the No Child Left Behind Act (2002) and the Individuals With Disabilities Education Improvement Act (2004), schools are challenged to provide programming that results in all students making progress in the general education curriculum, and to thoroughly consider the least restrictive environment for students with disabilities. In addition, with the recent increase in the identification of individuals with autism spectrum disorders (ASD) of 1 in 110 (Rice, 2009), teachers may have students with ASD placed in their classes for which they may be inadequately prepared. Simpson (2004) noted that the shortage of teachers who are qualified to work with students with ASD is "the most significant challenge facing the field" (p. 140). He went on to emphasize a lack of preservice teacher education programs that emphasize working with this population, affecting both general education and special education teachers.

Umbarger (2007) recommended that special education teachers help families identify effective interventions to facilitate functioning of the children with ASD. However, Wilkinson (2010) noted that with the changing knowledge base in ASD, parents, teachers, and other advocates will find it difficult to remain current in the areas of assessment and intervention. Therefore, Myles, Simpson, and deBoer (2008) found that professionals report being unprepared to meet the educational needs of students with complex issues related to ASD. Given the fact that the numbers of students with ASD have been increasing rapidly, and that teachers may feel inadequately prepared, parents of children with autism may be concerned that educational programming available through public school systems will not prepare their children for the future.

Some parents are turning to homeschooling as the option that works best for their families. In 1999, approximately 850,000 students were homeschooled in the United States. By 2003, that number had risen to approximately 1,096,000, and to 1,508,000 by 2007 (National Center for Education Statistics, 2008). Approximately 3.6% of the parents surveyed indicated that the most important reason they were homeschooling was because their children had special needs, and another 2.1% indicated that they chose to homeschool because their children had physical or mental health problems. Ray (2002) indicated that homeschooling may be the fastest-growing form of education today.

Researchers have surveyed parents' satisfaction with their children's educational programming (Moreno, Aguilera, & Saldana, 2008; Starr, Foy, & Cramer, 2001; Starr, Foy, Cramer, & Sigh, 2006) but none queried parents about their experiences with, and reasons for, homeschooling their children with ASD. Because prevalence of ASD is increasing,

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Table 1. Participants, Children, and Homeschooling Goals

Parents	Children (age in years)	Medical diagnosis	Homeschooling goals
Jackie	Amy (8)	PDD-NOS	Provide special diet, academics at grade level, do not want her labeled
Susan	Andrew (7)	Asperger's Disorder	Learning environment that addresses both his gifted and developmental demands, multiple breaks during the day, gluten-free diet
Christine	Mark (7)	Autistic disorder	Help Mark reach his potential, increase attention and language skills
June	Allison (20)	Asperger's Disorder	Learn self-advocacy, decrease sensory sensitivities
Donna	Chris (16)	Autistic disorder	Language development, increase positive behaviors/social interactions
Lori and Theo	Travis (12)	Autistic disorder	Stabilize health concerns, decrease aggressive behavior, increase language
Sally	Brandon (11)	Asperger's Disorder	Provide structure, decrease aggressive behaviors, eventual transition back to public school
Mary	Billy (8)	Asperger's Disorder	Learn social skills and how to express himself, learn how to make his way in the world, provide flexibility in scheduling
Lana	Donald (25) Jack (23) Joel (19) Selena (15) John (9)	Asperger's Disorder Asperger's Disorder Asperger's Disorder Asperger's Disorder Autistic disorder	Provide structure and routine, facilitate independence, teach life skills

Note: PDD-NOS = pervasive developmental disorder–not otherwise specified.

teachers perceive they are inadequately prepared, and the number of children being homeschooled is on the rise, the present study was conducted to interview parents who homeschool their children with ASD to explore their perceptions and experiences.

Method

Participants

To recruit parents for this study, I contacted local schools and the State Department of Education in the mid-western U.S. outside agencies who work with homeschooled children, and the Homeschooling Association. The agencies were asked to contact parents who homeschool their children with ASD to solicit interest in participating in the study, and to share my contact information. Neither the school districts nor the state department had data on the number of children with ASD who were homeschooled, so participants were recruited through the other agencies. This method of participant recruitment is referred to as purposeful random sampling, which is a qualitative research method used to identify participants of interest for the study and to develop a systematic way of selecting cases without having advanced knowledge of what the outcomes would be (Corbin & Strauss, 2007). Parents from nine families responded to my solicitation for participation in this qualitative study. Both parents in one family participated so that a total of 10 parents were interviewed.

Participants

The Institutional Review Board at Minnesota State University, Mankato, gave approval for the study to be conducted. After giving informed consent, participants and their children were given pseudonyms. Table 1 contains a summary of each of the participants' children and family goals for homeschooling.

Jackie had a master's degree in counseling psychology and worked as a psychotherapist, but she "gave up her career to stay home" and homeschool her daughter. Jackie shared that she would have liked to have worked part-time and still homeschool, but it was not possible for them as a family. Jackie's husband had two bachelor's degrees, one in Bible and one in youth ministry. Amy was a typically developing infant but started losing her skills at 12 to 15 months of age. At 15 months, she lost her expressive speech skills, and by 18 months, her receptive language skills were gone.

Both of the parents used applied behavioral analysis (ABA) methods when Amy was young. Jackie shared that even though she has been the main person working with Amy, her husband has always been very aware of Amy's issues and participated in programming from 10% to 30% of the time, especially when Amy was younger and the parents were "teaching round the clock." Jackie reported that Amy's father had been active in decision making about curriculum and did science experiments and math with Amy. He set up an "OT (occupational therapy) room" in the basement for sensory activities. At the time of the study, Amy was a talkative, friendly, outgoing girl, and her mother described her as being "profoundly gifted academically." Her mother explained that Amy completes work several years above her chronological age, particularly math, as she completes math work at the ninth-grade level. Amy loves Hannah Montana, the Jonas Brothers, math, and gymnastics. Amy is on a gluten-free and dairy/egg-free diet. Her mother reported that if Amy was off the diet, her autistic traits would return (i.e., she would "stare into space, would not respond when being spoken to, would have a processing glitch and limited attention, and her developmental ability would drop by several years"). Amy had a younger brother who was not diagnosed as having an ASD.

Susan had a master's degree in library science and worked part-time as a librarian in a city library. Her husband had a PhD and worked part-time as an attorney. Initially, Susan worked full-time while her husband stayed home with their son because she had a better health insurance plan, which they needed for services and therapies. At the time of the study, Susan worked part-time on the weekends to stay at home with Andrew during the week. Susan's husband worked evenings because he had a flexible schedule and could work around the needs of their son. Andrew received his diagnosis at the age of 3½ years. Andrew's interests included science and history. Results of an academic achievement test indicated that he was at the fifth-grade level overall in academics. His mother shared that Andrew struggled with sensory sensitivities, such as with certain foods and loud music. He received speech-language therapy for early expressive language skills and now has good language skills, although he continued to struggle with expressing his thoughts and feelings. Andrew had been on a gluten- and casein-free diet since he was 5 years old.

Susan was the "primary educator" and did the social networking, curriculum planning, and most of the teaching. Her husband engaged Andrew in music and hands-on science activities, as well as participated in Saturday activities with him (e.g., going to Lowe's and Home Depot, taking archery classes, and building rockets). Susan's husband kept records for insurance and tax purposes. Andrew was their only child.

Christine had a master's degree in early childhood special education and a bachelor's degree in speech-language pathology. Her husband had a high school diploma. They had three children, two of whom were on the autism spectrum. Mark, the child being homeschooled, was 7 years old. His older sister was not on the autism spectrum, whereas the younger one was. Christine did not believe she would homeschool the youngest daughter, because she felt the child could "complete schoolwork and fit in with her peers and the school setting." Mark received early intervention services such as early childhood special education programming through his school, occupational therapy, and intermittent speech therapy. His mother reported that they "tried it all," in terms of possible therapies, including gluten- and casein-free diets and supplemental vitamins. Those therapies did not help Mark, but his parents found success with ABA. Christine stated that her husband's involvement in the homeschooling process was minimal. He worked with Mark, but mostly on the family skills programming set up by the ABA provider. Christine believed that her husband's minimal involvement in actual programming had more to do with her being a certified teacher who provided ABA therapy in the past and worked with children on the autism spectrum when she was a teacher. Christine's husband works full-time and agreed 100% with the decision to homeschool. Mark liked to draw and color, especially on his chalkboard, and he liked movies and swimming lessons. Christine described Mark as a "happy and loving boy, with lower communication skills and lower cognitive ability."

June and her husband both had PhD degrees, and June worked full-time as a college professor in physics. Her daughter, Allison, had attended school with increasing difficulties until midway through the seventh grade. Her parents were told that if they "wanted services for her," she would have to go to a different school. The parents tried a different school, believing, as they were told, that "she would have much more individual time with teachers." Those "teachers" were actually paraprofessionals with no autism training. June explained that Allison "spent 80% of her time with a para, and 20% with the supervising teacher." At that time (2002), the school district did not have programming, services, or trained personnel to help Allison or her parents. June shared that she and her husband

> called several nearby school districts, and learned that they basically all had the same program—mainstreamed half the day and in special programming the other half of the day. The mainstream half of the day was the part that was giving her trouble.

After discovering that private and parochial schools could not provide the necessary services for Allison, it was a "mutual decision" between June and her husband to homeschool Allison. Homeschooling consisted mostly of licensed teachers providing direct 1:1 teaching at home. June reported that Allison's biggest problem all along was her sensory difficulties, which "severely limit her ability to integrate in society." When she was younger, Allison was given ear plugs to wear because of her auditory sensitivities, but she did not like wearing them. In third or fourth grade, it was Allison's parents who thought to give her ear muffs to wear instead, and she still wears them now. In fact, her auditory sensitivities have gotten more severe, as have her depression, anxiety, and obsessive-compulsive tendencies. June noted that she always had more responsibility for Allison than her husband but that it was more shared during her years of homeschooling. Her husband took care of all the legal and tax paperwork. June filed the paperwork with the district and ordered the curriculum, whereas both parents interviewed teachers and helped choose curriculum. Allison lived at home and volunteered at a veterinarian's office as a cuddler for abandoned cats. She was accompanied by one of her former homeschool teachers a couple of times a week. She had an older brother who was not identified as being on the autism spectrum but was "gifted in the sciences" as were the parents, according to June.

Donna had a bachelor's degree in teaching and was a principal project manager at a health care company. Her husband had a bachelor's degree in electrical engineering. They had Chris and his twin sister who was not identified as being on the spectrum, although she had delays in language development as an infant. Chris had an older sister with a diagnosis of Asperger syndrome. Chris was happy and open to new things, but according to his mother, he had no social filter regarding girls. He "perseverates on girls and gets information from them or from others, then googles them to find where they live." At the age of 4, he started receiving ABA programming after his mother attended a conference on ABA strategies. Chris received 30 to 60 hr a week of ABA therapy at home until fifth grade when his parents transitioned him to public school. Donna shared that her husband had been involved, especially in decision making. She usually did more of the ABA programming, although her husband conducted programming with Chris in the evenings when he was home. She pointed out that therapists did much of the programming/schooling. At the time of the study, Chris attended high school where the teacher provided ABA programming, as monitored by a psychologist from an outside agency.

Lori and Theo were the parents of Travis, who functioned on the lower end of the autism spectrum. Lori had an MBA and was a business consultant, whereas Theo had a technical degree and worked in the billing department of a safety consultant agency. Travis had significant gastrointestinal and metabolic conditions, including inflammatory bowel, severe acid reflux, and mitochondrial dysfunction. He experienced "failure to thrive" four times and had major bouts of diarrhea, resulting in significant weight loss. Travis had been on a gluten- and casein-free diet since he was 3 years old, and took Prednisone, Enticort, prescription Prilosec, and multiple vitamins. Travis was a typically developing infant until 12 months of age when he lost all skills, particularly speech. When he was 3 years old, his parents started using the Son-Rise program with Travis. They tried to enroll him in public school, but Travis displayed severe behaviors while in school, and his parents reported that he regressed in some of the skills he had previously mastered. The parents and school personnel disagreed regarding programming issues and behavior planning. At the time of the study, Travis was at home, with a team providing Son-Rise programming full-time. Lori commented that her roles and her husband's roles were equal and "that we always need to discuss changes, which we do with the whole team, especially when there is a medical component." The husband-and-wife team established goals together. She shared that she and Theo divided tasks with care and according to their strengths. She said she was "better at laundry and Theo is better at cooking." Travis' parents believed that vaccinations caused his autism. Travis had a typically developing older brother who helped with Travis' treatment plan and programming.

Sally was a full-time teacher, working on her master's degree in special education with an emphasis on ASD. Her husband had a 2-year technical degree and was the president/chief executive officer of an agricultural production company. They had two children, one of whom had an ASD. Brandon had a special interest in vehicles, "anything with a motor," and fishing. He had difficulty with loud volumes and got wound-up when tired. He conversed more and better with adults than with peers. His writing skills were a big problem for him. He attended public school from kindergarten to partway through third grade. He had an early diagnosis of attention deficit hyperactivity disorder (ADHD) and had difficulty with listening, following directions, and understanding danger, and did not know how to get attention appropriately. His mother reported that some teachers "clicked" but things fell apart in third grade. This teacher and crisis team frequently resorted to restraining Brandon and suspended him from school several times. He fell behind academically and his parents pulled him out of school. He had been homeschooled for 3 years and his parents hoped to transition him to partial school days midway through the year (sixth grade). Sally noted that her husband was very involved with Brandon but "not so much with the homeschooling part." Her husband got Brandon ready in the morning, took him to medical appointments during the day, and did "all the fun stuff like go-karting, snowmobiling, going to races, and fishing." Sally and her husband were in total agreement with homeschooling and worked as a team to determine how to best meet Brandon's needs. Brandon had an older sister who was not on the spectrum.

Mary was two semesters away from a master's degree, and her husband had a bachelor's degree in accounting. She stayed at home to homeschool their two children, one of whom was on the autism spectrum. Mary described Billy as being "loving and hilarious," and very interested in trains and LEGOS®. Billy could follow directions to build a 5-foot structure but was "very disorganized and cannot clean his room to save his life." He was given an educational diagnosis of noncategorical delay at age 3½ years and attended early childhood special education services, then transferred to a regular preschool setting. Things went well until partway through his first grade year, when his teacher left on maternity leave and everything "just fell apart" with the substitute teacher. Billy could not adjust to this teacher, who was not necessarily following the programming of the regular teacher. His aggressions increased, and he was sent to the resource room "to calm down" but soon was being sent all of the time. Billy's parents kept him in school through the end of the year with his mother in the classroom, serving as the paraprofessional on most days. Mary shared that "we would not have been able to have him in the mainstream classroom without that happening." After that school year, Billy's parents started homeschooling. Mary provided the majority of the homeschooling programming although her husband taught the math and science curricula. Mary referred to her husband as the "science and math guru." Her husband talked every night with Billy about what he did that day and what Billy learned, and he posed questions to help Billy demonstrate understanding of the day's materials. Mary referred to these discussions as "having conferences every night." Mary and her husband provided year-round homeschool programming. Billy's older sister also was being homeschooled, although she was not identified as being on the autism spectrum.

Lana had a bachelor's degree in nursing but was not currently working even though she had been actively recruited to return to nursing as a bilingual surgical nurse with a high salary. She chose to stay at home to homeschool all five of her children, and she reported that all of them have been diagnosed as being on the autism spectrum, "ranging from pervasive developmental disorder–not otherwise specified (PDD-NOS) to regressive autism." Lana's husband had a 2-year college degree and was a postmaster with the U.S. postal service. The three oldest children (19, 23, and 25 years) attended college and lived at home, whereas the two youngest (9 and 15 years) were homeschooled. The oldest child was originally diagnosed with ADHD, and the school informed the parents that the two oldest children needed to be "medicated or they can't be in school." They took both children out of school and never had any of their other children even start public school. They believed that vaccinations were the cause of at least the youngest child's autism, due to the fact that he lost all skills within a week of being vaccinated at age 2½ years. Their children received a large variety of services, ranging from music therapy to speech and occupational therapy, and gluten- and casein-free diets.

Procedures

As the parents contacted me, I sent a description of the study, along with consent forms and a copy of the interview questions, and set up a time and place to meet for the interview. The parents were given the opportunity to ask specific questions before the initial interview, via phone or email, and were able to prepare for the interview by having the questions shared with them ahead of time. Initial interviews for each of the 10 participants from nine families started with informal conversation for the purposes of getting to know each other, developing rapport, and for obtaining personal and background information. After this was accomplished, the actual interviews began. The appendix contains the initial set of interview questions. Follow-up interviews were conducted via phone and email with all nine families, as necessary, for the purposes of clarifying previous information and obtaining additional information regarding their perceptions and experiences with homeschooling.

Data Analysis

All interviews were audio taped for subsequent review. After each interview session, I reviewed the tape-recorded information, transcribed the sessions, and made anecdotal notes regarding the conversations and email responses. As the notes were read, recurring ideas and thoughts were documented and emerging patterns were identified. Data were analyzed using an open-coding procedure. Throughout this process, patterns and codes were identified by isolating topics/comments/issues, counting the number of times they occurred, and their consistency throughout the data.

As the field notes were read, I wrote down a word or phrase that identified the main idea of the paragraph. Twenty words/phrases were identified at this point. These topics included parental responsibilities and education, conflicts with schools, bullying, medications, knowledgeable and resourceful parents, availability of services outside the school system, monitoring, and curriculum. I utilized peer review as a way to ensure reliability and validity of the data. A colleague who had not been involved in the research reviewed the transcribed tapes of the interviews and coded responses by paragraph. In the peer review, only 12 codes were identified; however, all of them were the same as, or very similar to, the 20 codes I identified.

After data were coded, concepts were identified. I grouped the concepts and then named them according to the characteristics of the grouped concepts. Six categories were named at this point including advocacy, family, parent advice, community, disagreement with school, and interventions/programming. Some of the original 20 codes were assigned to more than one category whereas others were clustered together into one specific category only. This occurred while I continued to narrow and categorize the codes and rework the configurations to clarify patterns in the data. Eventually, four themes emerged.

At each point in the process, I utilized member checks as a way to ensure validity. This strategy involved taking the data, analyses, and conclusions back to the participants so they could read, review, and comment on the information. Participants were asked to comment on accuracy and provide clarification if needed. Each set of parents was contacted at least three more times after the initial interview. Reasons for follow-up contact included clarification of programming, medications, and the events that led up to the decision to homeschool, and the roles and responsibilities of each parent. In each case, there were one or two corrections made. Finally, the parents each reviewed the themes that emerged from the data, and there was 100% agreement from the participants. Parents made comments such as

Theme 1: Parents who homeschool their children with ASD are knowledgeable about ASD, and are involved, watchful parents who want only the best for their children.

Theme 2: The specific situations and treatment programs the homeschooling parents use are very diverse, unique, and individualized, and the parents have persevered in obtaining information they need to develop a program they believe works best for their child.

Theme 3: Parents who homeschool their children with ASD have different opinions about what needs to be addressed from what teachers and public school systems are doing.

Theme 4: Parents who homeschool their children with ASD believed that homeschooling is a major decision and that both parents need to be in agreement with this choice.

Overarching Theme: Parents who homeschool their children with ASD feel as though they have found a treatment plan that works, and their perception has been that the school has been either (A) not willing and/or
(B) unable to provide that treatment effectively.

Figure 1. Themes from data analysis

"These themes do apply to us and our family," "The four themes you listed are absolutely correct from our experience," "The themes seem right on to me!" "I would agree that these statements apply to my husband and me," and "You did a great job of capturing us!" With the identification of these four themes, an overall conclusion theme also was identified.

Care was taken to ensure reliability as well by creating as much similarity as possible. Procedures were explained the same way to all participants, all participants were asked the same questions, all interviews were audio taped and reviewed immediately after interview sessions, and the same information regarding the study (in progress and final) was shared with all nine families.

Results

During data analysis, four themes and an overarching theme were identified. Figure 1 contains the themes that emerged from the data analysis. The following is a discussion of these themes.

> *Theme 1:* Parents who homeschool their children with autism spectrum disorders (ASD) are very knowledgeable about ASD and are involved, watchful parents who want only the best for their children.

The parent participants demonstrated advanced knowledge about ASD, in terms of facts, terms, treatment methods, national experts in the field, and diagnostic criteria. They have researched, searched out, found, and used every imaginable therapy and treatment method available to them, even when it meant traveling to be trained in a specific method. Parents from these nine families have persevered in their pursuit of programming that worked and believed it was their responsibility to do this for their children. Many of these parents recognized early delays and had concerns about their child's development. Several of them were told "to wait" or that they were "overreacting" by their pediatricians and other professionals, and had to actively pursue a diagnosis and treatment.

Donna noted that she was "given grim statistics and showed out the door" after pursuing an evaluation and autism diagnosis at a noted autism center in her state. This was after being called by her son's daycare, demanding that she come pick him up after only 7 hours. She only somewhat laughingly shared that "Chris failed daycare after 7 hours!" Lana shared her experiences when receiving the diagnosis of autism for her youngest son as recently as 2004 and was given the "old song and dance routine" by a behaviorist who informed her that her child would "never be able to talk, read, write, be potty trained, or function in society." Lori and Theo noted how many times they had to pursue treatments and a proper gastrointestinal diagnosis from the doctors. Lori shared that "Travis's doctor sent us away and gave us drugs for him for his behaviors, and did not believe us that he had major stomach issues. It wasn't until we were on TV on an autism special that she contacted us," expressing an interest in treating him for what they originally asked for.

Some of the parents expressed their belief that it is their responsibility to homeschool their child so he or she could receive the programming desired by the parents. Lana expressed her belief in educating her children at home by sharing that

> they're better off at home. Parents have a lot of rights as human beings, but we also have a lot of responsibilities and it is not right when parents show up at school with their lawyers saying 'you have to do this no matter what.

Mary echoed similar thoughts when she stated that she wants her son "to be successful and it's my job as his parent to help him be that." She believes that Brandon will become the engineer that he desires to be.

> *Theme 2:* The specific situations and treatment programs the homeschooling parents use are very diverse, unique, and individualized, and the parents have persevered in obtaining information they need to develop a program they believe works best for their child.

Just as there are a large number of available treatments and methods used with individuals with autism, these parents who homeschool their children used a wide variety of approaches. Eight of the 10 parents shared long lists of the treatments and strategies that they had tried with their children. These included speech therapy, occupational and physical therapy, music therapy, feeding therapy, social skills classes, chiropractic services, auditory integration therapy, applied behavior analysis (ABA), early childhood special education services, special diets, supplemental vitamins, paying for private tutors/teachers to work with the child at home, and the Son-Rise program. Susan felt fortunate that her "insurance paid for everything and anything," so she and her husband tried "every therapy and treatment method" they could find. Their son participated in 10 different methods and strategies. A gluten-free diet along with challenging academic work has proven to be most successful for Andrew.

Lana expressed the frustration that came with a lack of services and with trying to find a treatment that worked. She stated that she wanted her son to have ABA training but after "waiting for 4 years, was told he was a year too old." She said that "as a parent, you try anything that is available to you," but looking back, she realizes that ABA would not have been a good methodology for her son. She shared that she "would not have been able to watch the treatment being conducted and would not have been able to do it [herself]." Lana utilized a life-skills approach to teach her children how to function well in society. She shared that she was not afraid to "sabotage their world" so that they had to learn to deal with consequences and not have accommodations that make things too easy for them, as that is "not the real world."

Travis's parents traveled to Boston to receive training in the Son-Rise method and used it at home with him from the time he was 3 years old until he was 8, when they tried to have him attend school. His speech and other skills had improved dramatically from the time he originally lost them, but according to his parents, Travis stopped talking completely over the 4 months he was in school. He was taken out of school, then started back again a couple of years later. After just a few months in school this time, his parents took him back out again because of behaviors he exhibited at school (e.g., he had broken windows and chairs, and smashed windows with his hand). His parents knew he was in increased gastrointestinal pain, and they believed that "with more pain came more acting out behaviors" and that "the teacher stopped trying to teach him anything" because of the aggressive behaviors.

Donna stated that they found success early on with ABA but had tried other methods first. For 5 years, her son Chris was on a gluten- and casein-free diet, but she took him off the diet at the age of 13 because "there was no real change in his behaviors." They did, however, discover his sensitivity to apples and corn, and work to prevent him from eating either of those. According to his mother, ABA has proven most successful for Chris.

June shared that Allison received OT and speech services in preschool but once she was school aged, no beneficial services were provided. At that time (8 years ago), she and her husband "were not informed of services in the community" and were "at a loss of what to do." Current commonly known strategies, such as Social Stories™, visual schedules, and sensory integration, were not used at that time in her daughter's school and she was not aware of services in her community.

> *Theme 3:* Parents who homeschool their children with ASD have opinions about what needs to be addressed that differs from what teachers and public school systems are doing.

The parents in this study were very clear about what they wanted their children to be prepared for, and how that differed from the typical public school focus on academics and test scores. They wanted their children to be able to function in society as adults and be prepared for the real world.

Mary wondered how children can learn important skills when there are so many students in one classroom. She asked, "When else are you ever in a group of 25 people at one time?" She believed that children are "not being properly trained in how to interact with the world" because of that. Mary also was frustrated with the way her son's school dealt with discipline issues. "Schools often treat students in a punitive manner and use a cookie cutter approach to discipline. Billy kept repeating the same behavioral pattern because he didn't get what he did was wrong. No one explained that to him." Instead of just suspending him, she wished that the school would have addressed skills that were important for him, such as "social and coping skills, so that he could express himself well."

Lana felt that schools did not provide enough structured programming and that accommodations made life too easy for these students. She stressed the importance of preparing her children for the adult world by requiring "a daily routine, strict schedule, and functional skills." This included dressing and grooming properly in the mornings before school or work. "We do not sit around in pajamas" when doing schoolwork.

Susan focused on providing critical thinking activities for Andrew, insisted on him reading one book per day, insisted he work on handwriting skills, and challenged him academically. She shared that she was told by the school that he would be in grade-level curricula if she enrolled him, and she knew he would not be challenged. Lori and

Theo shared their frustration that the school insisted using certain techniques, such as the picture exchange communication system (PECS), even though they wanted Travis to continue to develop speech. With PECS, he "stopped talking over a 4-to-5 month period." His speech improved once they started homeschooling. They wanted Travis to learn enough to function in society, even though "he may need some help." The school's goals for him were to print his name, even though "he could already write many other words, because his teacher commented that his penmanship wasn't good." Travis' parents focused on him getting healthy rather than working on academic skills. They questioned how the school could expect Travis to learn when he was so sick. They believed that it was imperative to "take care of his medical issues before learning!"

Chris was somewhat unique as compared to the other children in this study. His mother, Donna, shared that Chris returned to the public school in fifth grade but struggled all year with that transition. In sixth grade, at the insistence of the parents, the school hired a personal care attendant who knew Chris well, to be his 1:1 paraprofessional. Donna shared that the school district was not "open to doing ABA," so they moved him to a different school district when a new teacher, who had received minimal training in ABA principles, was hired. Although this teacher was "only somewhat knowledgeable about ABA," Donna reported that the teacher developed a rapport with Chris and was receptive to monthly visits from an ABA-trained clinical psychologist that the parents hired to observe the teacher and Chris at school. The psychologist provided the teacher with recommendations for ABA programming, taught her how to implement them, and monitored her use of these techniques. Donna reported that if this teacher and the school had not been receptive to the private consultations, she and her husband would have homeschooled Chris again with private tutors.

All of the parents discussed policies in their school districts regarding communication and interactions with the school while homeschooling their children. All of the parents shared the need to send a letter of intent every year to the school, explaining that they were homeschooling their children and outlining what they planned to do. In most cases, the parents had to pay for testing completed either annually or at the same time as their child's peers who attend public school (e.g., 4th, 8th, and 10th grade). Results needed to be sent to the schools but according to several of the parents "nothing is done with those results." The schools did not have to approve programming, and in almost all cases, did not provide resources or suggestions. Jackie shared that her school district had a lending library for all parents, and she found resources and materials there. However, all of the parents had to find materials and curriculum on their own and at their own expense. A couple of the children had Individualized Education Programs (IEPs) and the school provided programming for special needs and gave suggestions to the parents. For example, Andrew had an IEP for fine motor delays, and an occupational therapist from the school district provided direct services. None of the parents felt any pressure from the schools to enroll their child in the public school, except for Donna, who was pressured by the first school district, even though they would not provide the ABA programming the parents requested. In addition, school districts did not monitor students who were homeschooled, which was a concern of most of the parents. Theo was concerned enough about the lack of monitoring that he called the state department and asked if "anyone was going to monitor us." He was told "no." Mary shared that it was "easier to be left alone but that some monitoring from the school needs to be in place; there should be some kind of checks and balances in place."

Theme 4: Parents who homeschool their children with ASD believed that homeschooling is a major decision and that both parents need to be in agreement with this choice.

All of the parents felt that it was important to communicate with each other to make a collaborative decision about homeschooling. June recommended that parents "choose an option that works for you and your family." Their decision to have a private tutor teach Allison at home was the right decision for them. "I would have gone crazy if I had been home all day every day with her," and having a private tutor at home to teach and work with her made this possible. June also shared that for a number of years, basically, "one parent's income paid for the private tutor" for their daughter.

Donna shared that it was much less stressful for her to homeschool her son rather than "fight with the school on every issue" and that she and her husband felt that the great financial sacrifice for ABA training was worthwhile. She also explained that "money is a big issue, but if one parent can stay at home and do this, that's fabulous." Christine believed that it was a necessity for parents to agree on this choice, and "because of all the other stress you have to deal with having a child with autism," parents cannot disagree on the homeschooling issue. She suggested, too, that parents "have to know that they really want to do it and can commit to it."

Jackie advised parents to "pray about" the decision if they are spiritual and determine "what's best for your child." She shared that parents need to set rules, such as "no children getting out of bed and coming downstairs after 10 p.m. and going out to eat without the children once a month" because this is "hard on the family, a huge sacrifice." Theo suggested that the high divorce rate among homeschooling parents may be because they "disagree on approaches" to be used with their children, and it was important to come together with programming ideas. Lori added that it was important that "not one parent does it all."

Sally shared that she heard about an 85% to 90% divorce rate for parents with children with autism. She suggested that parents "think long and hard about how it is going to work, and honestly think about whether your marriage can handle it." Lana also commented on the 85% divorce rate, and heard that the decision to homeschool is difficult to make because "it is very hard, you have no free time, no vacation time, and limited finances." Susan stated that "homeschooling is not an education [sic] choice; it is a lifestyle choice, which will affect your marriage, your day's structure, and your relationship with your child. It is not a choice for everyone, but it can be the best choice for those willing to put in the effort to make it successful."

All of the parents recommended that others considering homeschooling trust their instincts to do what will be in the best interests of their child. They all echoed Christine's sentiments when she shared you "have trust in your decision; parents know their child better than anyone else does."

Although the exact roles and responsibilities of the parents were different in each case, each of the parents worked together to make decisions and support each other. In most of the cases, the mothers were the primary caregivers and planners, but the fathers were active in carrying out tasks, such as completing paperwork for tax purposes, teaching lessons, and planning activities. In some cases, licensed therapists or teachers carried out the majority of the homeschooling, and in others, the parents took on the role of "teacher" and trainer. All of the parents made the decision together to homeschool, and all believed that it met the needs of their child and of their family better than other options.

> *Overarching theme:* Parents who homeschool their children with ASD feel as though they have found a treatment plan that works, and their perception has been that the school has been either (a) not willing and/or (b) unable to provide that treatment effectively.

Susan shared that Andrew would never return full-time to school. School "would not provide all of the opportunities and experiences he currently is able to enjoy." He was a "twice-exceptional child"—gifted academically and having Asperger syndrome, and he needed a "learning environment that addresses both of these demands." She believed that the school could not accommodate his gluten-free diet and sensory overload issues. In kindergarten, he was scheduled to arrive at school before other students, as having so many students arrive en masse caused "major sensory overload" for him.

Jackie shared that "if Amy were allowed to go to school in an academic grade at her gifted ability level, she would thrive in school," but she was told by the school that there was no gifted program and Amy would be placed with peers her age. Jackie also experienced a lack of sensitivity when she was almost accused of child abuse by Amy's preschool teacher who fought her about Jackie's request for organic food for Amy. She does "not want to deal with that again" and knows that "the school would not be able to protect Amy from cross-contamination of food and assure rigid following of her diet."

Christine believed that Mark would not meet his "maximum potential at school because of his engagement difficulties," even though he had improved in this area. She took him out of school because the school "would not do ABA. I do not have anything against the school at all—it's just that he has made so much progress through ABA, and the school will not use this method."

Another positive aspect of the homeschooling situations was the wide variety of social activities that the parents worked hard to provide for their children. The following is a list of activities in which the parents and their children participate regularly. Mary assured Billy's participation in meals on wheels, tae kwon do, and Bible study play group. Lana insisted on regular church activities for all of her children. Susan scheduled homeschool physical education, friendship, and music classes for Andrew, along with weekly field trip to places in the community such as the zoo, library, theater, orchestra hall, planetarium, and museum. Sally arranged participation in the homeschool group for monthly activities for Brandon, with scheduled speech therapy and a social skills group at school. Jackie had scheduled Amy in many different activities, including regular church activities, gymnastics, gifted math class, and homeschool cooperative activities three times a week. Christine shared that Mark loved swimming lessons and participated in them for a number of years.

Susan observed that "most parents want to be left alone and do homeschooling," and Mary echoed this sentiment when she stated that "it is easier to not be bothered by the school." Theo summed it up well when he stated, "We have the right path for Travis now, and we aren't going to change it."

Discussion

The 10 parents from nine families in this study shared their experiences and perceptions regarding homeschooling their children with ASD. Overall, they believed that home is where their child was served best and that the school could not provide the opportunities and experiences for their children that they could. For the most part, they did not have negative comments to make about the school system; it was just that programming in the schools was not the best fit for their child. Holland (2005) described how her son started lagging behind academically after one good year in school, with an excellent teacher. She noted how he was placed with "children with severe deficiencies . . . who all needed customized intervention" (p. 19).

Several parents in this study shared the above concern. If their children were placed in special education, the parents believed they would be placed with students with more severe needs. However, if they were to insist on their children being in the general education classroom, the parents felt as though their children's needs could not be met there either. Starr et al. (2001) pointed out that higher-functioning children were generally placed in general education settings where teachers were less likely to have knowledge about the higher end of the autism spectrum. Gusman (2006a) noted that placing a child in a special education classroom for students with more severe needs may result in the child picking up negative behaviors from the other students. Roberts, Keane, and Clark (2008) described the debate over inclusive versus specialized placements for students with autism. Inclusive settings may not provide sufficient stimulation for higher functioning students, but these settings provided access to general education and interactions with typical peers. However, some believed that general education settings are unable to address critical areas of functioning.

Another concern of these parents was the fact that their children were thriving and growing academically and socially because of their homeschooling programming, and, for some of them, their children regressed and lost skills in public school settings. In a study regarding the analysis of educationally based programs, Reed, Osborne, and Corness (2007) found that educationally based programs were showing no improvement in the child's intelligence quotient, functioning, or adaptive behavior. Simpson (2004) outlined the foundational core of programming as "strategies designed to enhance skills in areas of deficit, environmental supports and modifications, and biologically based interventions and treatments." He also stated that these "elements are often absent from many school and community programs" (p. 139). In addition, no one intervention or treatment strategy is effective for all children with ASD and not all children will benefit in the same way (Wilkinson, 2010). Several of the parents expressed concern over the seemingly "cookie cutter approach" they felt existed in the schools.

The parents in this study believed that the socialization activities they provided for their children helped them develop better social skills than they would have in the classroom. Boyd, Conroy, Asmus, McKenney, and Mancil (2008) reported findings that may support the parents' perceptions in this study. They found that social initiations and interactions of children with autism more than tripled in 1:1 settings versus large group settings. The children's social interactions doubled during child-directed situations rather than adult-directed situations.

The parents in this study believed that their children have suffered, or would suffer, if placed in public school settings. They experienced schools as being unable or unwilling to implement the methods they believed to be best for their child, or they felt as though the schools could not provide the same opportunities the parents could. Gusman (2006b) shared five reasons why homeschooling may be best for children. These include the following: 1:1 instruction, which provides for optimal learning and maximized progress; environments that can be adapted more easily for the child's sensory difficulties; flexible scheduling with less time wasted on nonacademic tasks; better opportunities for more positive socialization; and incorporating children's interests into their schoolwork and studies.

A number of the parents addressed concerns they had about stress and that commitment of both parents is needed to successfully homeschool their children. They warned that parents who choose to homeschool must be in agreement with the techniques used and must support each other. Three parents made reference to the commonly believed divorce rate of 80% to 85% for parents of children with ASD, while explaining the need to make thorough, informed decisions about homeschooling. However, recent figures suggest that the high divorce rate is a myth and that the divorce rate for these parents is 65%, which is only 1% higher than for parents of children without autism (Doheny, 2010).

In a study completed by Easter Seals Society and the Autism Society of America, researchers revealed that 70% of parents of children with autism were concerned about their children's education, as compared with 36% of parents of typically developing children. Only 19% of parents of children on the autism spectrum felt that their children were receiving education to adequately prepare them for life, compared with 56% of parents of children without disabilities (Samuels, 2008). Whereas researchers such as Jordan (2003) and Kunce (2003) explained that students can make progress in classroom settings with appropriate interventions and behavioral supports, the parents in this study believed this was not true for their children. The parents in this study believed that homeschooling was the best option for their children.

Limitations

Although this study provides insights into the experiences of 10 parents from nine families who homeschool their children with ASD, the results must be interpreted with some caution. This study was confined to 10 parents who homeschool their children with ASD and who responded to a request for volunteers through recruitment efforts of the researcher. The information received from the participants was based only on their perceptions of their individual experiences with their children and schooling. I did not account for, or differentiate among, such experiences on the basis of gender, age, ethnicity, socioeconomic status, nationality, parents' education, or religion. Any similarities among the parents regarding education level, programming methods, and experiences with the schools were not planned, and no generalizations were made regarding all parents who homeschool their children. None of the parents knew each other, nor did they recommend any other parents for the researcher to contact. Therefore, the results of this study may not be representative of all parents who homeschool their children with ASD but does provide preliminary findings that may be of interest to others who are exploring educational options for students with ASD.

Appendix

Interview Queries/Questions

1. Educational level and employment for each parent
2. Describe your child, diagnosis, characteristics, strengths
3. Has your child ever attended the public school setting? What services did he or she receive?
4. Why did you choose to homeschool your child?
5. Please describe the programming your child receives through homeschooling
6. Are you required to have contact with the local school system regarding your child's education?
7. Did/does the school system have to approve your programming? Do they give you any advice or suggestions? Do you implement those ideas?
8. Have you ever felt pressured by the school system to have your child return to, or start attending, the public school setting? If you are currently homeschooling your child, would you ever consider having him or her attend public school? Why or why not?
9. Do you communicate with other parents who homeschool their children with autism?
10. What advice would you give to other parents who are trying to make the decision of homeschooling or not?
11. Do you have any advice for schools regarding educational programming for students on the autism spectrum?

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References

Boyd, B., Conroy, M., Asmus, J., McKenney, E., & Mancil, G. R. (2008). Descriptive analysis of classroom setting events on the social behaviors of children with autism spectrum disorder. *Education and Training in Developmental Disabilities, 43*, 186–197.

Corbin, J., & Strauss, A. (2007). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: SAGE.

Doheny, K. (2010). *Autism families: High divorce rate is a myth*. Retrieved from http://www.webmd.com/brain/autism/news/20100519/autism-famlies-high-divorce-rate- is-a-myth

Gusman, M. (2006a, June 16). *Homeschooling children with autism: 5 reasons why it works*. Retrieved from http://www/EzineArticles.com/?expert=Mary_Gusman

Gusman, M. (2006b, June 30). *Social skills and autism: Where's the best place for socialization?* Retrieved from http://www/EzineArticles.com/?expert=Mary_Gusman

Holland, O. (2005). *Teaching at home: A new approach to tutoring children with autism and Asperger syndrome*. London, England: Jessica Kingsley.

Individuals With Disabilities Education Improvement Act of 2004, 20 U.S.C. § 1400 *et seq*. (2004). (Reauthorization of the Individuals With Disabilities Education Act of 1990)

Jordan, R. (2003). School-based intervention for children with specific learning difficulties. In M. Prior (Ed.), *Learning and behavior problems in Asperger syndrome* (pp. 212–243). New York, NY: Guilford.

Kunce, L. (2003). The ideal classroom. In M. Prior (Ed.), *Learning and behavior problems in Asperger syndrome* (pp. 244–268). New York, NY: Guilford.

Moreno, J., Aguilera, A., & Saldana, D. (2008). Do Spanish parents prefer special schools for their children with autism? *Education and Training in Developmental Disabilities, 43*, 162–173.

Myles, B., Simpson, R., & deBoer, S. (2008). Inclusion of students with autism spectrum disorders in general education settings. In R. Simpson & B. Myles (Eds.), *Educating children and youth with autism* (2nd ed.), pp. 357-382. Austin, TX: Pro-Ed.

National Center for Education Statistics. (2008). *1.5 million homeschooled students in the United States in 2007*. Retrieved from http://nces.ed.gov/pubs2009/2009030.pdf

No Child Left Behind Act of 2001, 20 U.S.C. 70 § 6301 *et seq*. (2002).

Ray, B. (2002). *Research facts on homeschooling*. Retrieved from www.nheri.org/content/view/199/

Reed, P., Osborne, L., & Corness, M. (2007). The real world effectiveness of early teaching interventions for children with autism spectrum disorders. *Exceptional Children, 73*, 417–433.

Rice, C. (2009). Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, United States, 2006. *Morbidity and Mortality Weekly Report, 58*, 1–20.

Roberts, J., Keane, E., & Clark, T. (2008). Making inclusion work: Autism Spectrum Australia's Satellite Class Project. *Teaching Exceptional Children, 41*(2), 22–27.

Samuels, C. (2008). *Parents of children with autism pessimistic, survey says*. Retrieved from http://www.edweek.org/ew/articles/2008/12/16/16autism.h28.html?tmp=158837642

Simpson, R. (2004). Finding effective intervention and personnel preparation practices for students with autism spectrum disorders. *Exceptional Children, 70*, 135–144.

Starr, E., Foy, J., & Cramer, K. (2001). Parental perceptions of the education of children with pervasive developmental disorders. *Education and Training in Developmental Disabilities, 36*, 55–68.

Starr, E., Foy, J., Cramer, K., & Sigh, H. (2006). How are schools doing? Parental perceptions of children with autism spectrum disorders. *Education and Training in Developmental Disabilities, 41*, 315–332.

Umbarger, G. (2007). State of the evidence regarding complementary and alternative medical treatments for autism spectrum disorders. *Education and Training in Developmental Disabilities, 42*, 437–447.

Wilkinson, L. (2010). *Autism and Asperger syndrome in schools: A best practice guide to assessment and intervention*. London, England: Jessica Kingsley.

Bio

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