

Research Articles

Family Impact of Children with Autism and Asperger Syndrome: A Case for Attention and Intervention

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This paper examined the impact of families living with young children ($n = 15$) with High Functioning Autism (HFA) and Asperger Syndrome (AS). A mixed-methodology design investigated parent perspectives and emerging themes encompassing the diagnostic process, the impact of child characteristics, accessing services, and parental concerns for the future. Results indicated that families experienced both positive and negative impact of having a child with HFA/AS; externalizing behaviours correlated negatively with positive family impact, $r(13) = .69, p < .01$. Findings have implications for medical professionals, families, and community partners in reference to providing effective resources for families experiencing HFA/AS.

Keywords: Autism and families; High-functioning autism; Family impact, Asperger syndrome

Introduction

Increased attention in media and research has contributed to a broader understanding of High Functioning Autism (HFA) and Asperger Syndrome (AS). Although much attention is given to autism spectrum disorders as a whole, it is important to understand characteristics of those individuals functioning at the more cognitively able end of the spectrum. While debate continues over diagnostic and definitional issues [1-3] the distinctive needs of individuals falling in Level 1 “requiring support” within the Diagnostic Statistical Manual-V [4], as most individuals previously diagnosed with HFA/AS would, is of continued importance. This is especially critical as unique patterns of behavior related to social competency, co-morbid disorders, and other long-term outcomes specific to HFA/AS may have distinct impacts on families and the educational experience.

The purpose of this paper is to explore the impact of children with HFA/AS on their families, from both concurrent and future perspectives. In so doing, several considerations have been posed. One is that child characteristics may have differential impact on families, particularly the co-morbidity of mental health disorders. While social impairments may be somewhat less obvious in the family context, the consequences of social deficits in the school context, which can result in individuals with HFA/AS being bullied and, ultimately, having clinical levels of depression may also increase stress on parents [5]. Finally, simply navigating the public school system and other service delivery programs may result in increased stress on parents as well.

Role of co-morbid disorders in family impact

Individuals with AS and HFA are at heightened risk for poor mental health outcomes [6], such as anxiety, depression, and mood disorders [7]. With AS and HFA being foremost social disorders the associated challenges, such as peer rejection, correlate highly with levels of depression [8]. On the other hand, predictors of depression for higher functioning children seem to include knowledge of one’s social competence and membership in a social group [9,10]. In

addition, parent-ratings of child awareness of disability were related to higher levels of depressive symptomatology [11]. These findings indicated that individuals who recognized their social deficits experienced poorer mental health outcomes as compared to those with lower levels of awareness.

When the relationship between Intellectual Quotient (IQ) and depression were further examined, participants with higher full-scale IQs tended to have lower rates of depression [12,13] possibly indicating that intellectual competency in individuals with HFA/AS protects against depressive symptomatology. An examination of long-term depressive characteristics by Barnhill and Myles [14] reflected a stable pattern of depression into adolescence where up to 80% of participants with AS in their study used prescription anti-depression medication. Similarly to the general population, a family history of depression is typical for children with ASD who have depression. This is a notable finding as family resources may be further taxed when parents are concurrently facing personal mental health challenges and child depression.

Long-term impact on families and individuals with HFA/AS

Although the characteristics of HFA and AS continue to be manifested across the lifespan, the course of development differs between individuals [15-17]. A plethora of research seems to indicate that symptoms of ASD show improvement into adulthood [18-21], with adults displaying less restricted and repetitive behaviors and interests than adolescents with ASD [22]. Furthermore, IQ scores greater than 70 in childhood are a predictive characteristic of better outcome in adulthood [23].

As mentioned above, social relationships continue to be problematic into adolescence and adulthood and impact successful employment [22,24]. Orsmond, Krauss, and Seltzer found that almost half of their 234 adolescent and adult participants with ASD had no relationships with peers outside of structured social activities

like school or work [25]. Participation in social and recreational activities included internal and environmental predictors. Internal predictors were more independent skills, higher social behaviors, and less internalizing behaviors, while environmental predictors included maternal involvement in social activities, receipt of more services, and participation in inclusive settings.

Although autism related characteristics have been shown to decrease over time, the challenges that continue into adulthood may cause concern or worry for families of children with HFA/AS. Despite average to above average IQs, these population experiences poor vocational outcomes [26] and limited relationships with others in adulthood. As their strongest advocates, families of children with HFA/AS may find themselves under stress throughout the lifespan, as they cope with finding appropriate diagnostic and educational services.

Family stress

Research specifically investigating stress levels in families has differentiated findings between families of a child with HFA/AS as compared to families with typically developing children. When examining social deficits and acceptance in parents of a child with HFA/AS [27] found that parents of children with autism had significantly higher levels of concern about their child's achievement, self-esteem, stress-coping, learning difficulties, and incidences of bullying than did parents within an unaffected control group. In addition, mental health, social acceptance, and socialization have also been identified as areas of concern [28,29]. In an internet survey conducted by Little and Clark, the primary parental concern for children with autism ages 3 to 21 was the social "survival" of their child. Parents expressed concerns that their child would never make friends, not adapt to various social situations, suffer from depression, and would fall prey to victimization. For instance, the consequences of social impairments that children with HFA/AS exhibit may have consequences for a child's mental health that ultimately increase stress on parents. Van Roekel et al. found that a lack of social competence in the school context resulted in increased instances of bullying when compared to typical peers [5]. These negative social experiences have wide ranging consequences for the child, including poor self image and clinical levels of depression or anxiety, compounding parent responsibility to provide appropriate support.

Another stressful component of parenting children with HFA/AS is the diagnostic and planning process. Parent reports indicated that time-to-diagnosis, lack of full parental participation in educational planning, and the failure of using intervention data to inform educational plans were especially taxing [30]. The impact not only has an effect on parents, but also siblings and interpersonal relationships between family members [31]. In one study, investigated variables that impacted stress level and relationships for 20 couples with children with ASD and 20 couples with neuro-typical children [32]. Significant differences emerged between the two groups indicating that couples who had children with ASD experienced more intensive and frequent child behavior problems, higher stress, less relationship satisfaction, and less overall social support. While providing some insight, this study focused on the entire spectrum of ASD, causing one to wonder if similar outcomes would be found if the study differentiated to HFA/AS.

Another important study by Kelly, Garnett, Attwood, and Peterson used structural equation modeling to investigate family conflict and cohesion [33]. The findings indicated that higher levels of family conflict predicted anxiety/depression in children with ASD and that anxiety and depression predicted more ASD symptomatology. Consequently, behavioral characteristics of ASD seem to have a circular impact on family stress, mental health, and the expression of autism.

Mothers appear especially vulnerable to experiencing stress related to their child with ASD [34-39]. While fathers reported significantly less stress than mothers in relation to parenting [40], stress profiles in mothers of adolescents and adults with ASD indicated three times more stressful events per day and twice as many stressful days overall when compared to mothers of typically developing children [41]. Specific variables contributing to stress were fatigue, work intrusions, care of child, chores, and fewer leisure opportunities. In addition, parents of children with ASD have significantly higher divorce rates than families of children without disabilities [42]. As many of these studies focus on families of individuals with ASD as a whole focusing on the family impact of having a child on the higher end of the spectrum needs to be further explored.

Role of supports

Supportive social networks provide beneficial reductions in stress for parents of children with ASD [43,44]. Ironically, the families in most need of social networks received the least support. For example, frequency of support from family members and relatives tended to be lower for families with a child with HFA than for families who had typically developing children [45]. When investigating family environment and social support outcomes for families of children with Asperger syndrome, learning disability, or typical development, parents of children with AS rated themselves as demonstrating expressive feelings less often, but rated their family organization higher than the other two groups [46]. Their perceptions of number of friendships and social supports were also rated as significantly lower than the groups with learning disability and typically developing children. When family styles were taken into account, parents of children with autism who described their families as enmeshed reported more positive coping strategies than disengaged, separated, or even connected families [47]. Overly involved and protective family patterns may be beneficial for families of children with autism.

Formal supports such as respite care, parent training, treatment, and support groups can contribute to positive impact on the family system. A meta-analysis by Chan and Siagoos on the impact of respite care for children with developmental delay concluded that, when respite care was utilized, there was a reduction in parental stress and an increase in coping abilities [48]. Considering that parents of children with ASD are less likely to engage in recreation and leisure activities, they may be less likely to access respite or babysitting supports, with some potential jeopardy to coping and mental health [49].

Purpose of study

With the research suggesting co-morbid disorders, behaviors related to social competency, a lack of supports for families, and other long term outcomes associated with HFA/AS have and impact on overall family functioning and stress, the current study examined

family perspectives of children with high-functioning autism and Asperger's syndrome in order to explore these themes in more detail. Child impact on the family and struggles families faced obtaining a diagnosis and access to services were explored. Furthermore, parent perspectives were ascertained on the future of their child. Four related questions were addressed utilizing a mixed method approach in order to develop a more complex view [50] of the impact of raising a child with HFA/AS.

1. How do families of children with High Functioning Autism and Asperger's Syndrome (HFA/AS) view the process of diagnosis and obtaining services?
2. What is the impact, both positive and negative, of having a child with HFA/AS?
3. What advice do parents have for other families with a child recently diagnosed with HFA/AS and the professionals that work with them?
4. What future concerns do families of a child with HFA/AS express?

Method

Participants

Data for this study were collected from 15 families who had children diagnosed with High Functioning Autism (HFA) or Asperger Syndrome (AS) living in Southern California. Families comprised a sample of convenience, recruited through autism agencies and an ongoing research project that had access to parents of children with HFA/AS. Professionals at each agency, and the researchers, identified several children who met the inclusion criteria, and their parents were given or mailed information about the project. From this mailing, 13 families chose to participate by contacting the principal investigator. In addition, two families were recruited through parent referral bringing the total to 15 participants.

Children were of preschool or early elementary school age, with a mean of 8 years (range: 4 to 10 years). All had an existing diagnosis of high functioning autism or Asperger syndrome, obtained by licensed psychologists who worked for the participating agencies, prior to participation in this study. It was a generally Caucasian, male sample (83%). About half of the children (55%) attended school in general educational settings with typical peers.

Parents were relatively young, well educated, and most were partnered (87%). The mean age for mothers was 40 years (range: 22 to 53 years); 50% of whom were employed, and 44% had at least a bachelor's degree. The mean age of the fathers was 46 years (range: 30 to 69 years); 93% of whom were employed, and 47% had at least a bachelor's degree. Although there was variability in family income, 87% of families earned over \$50,000 per year. All child and family characteristics can be found in Table 1.

Assessments

Parents participated in home interviews that lasted approximately two hours. These visits were conducted by research assistants who received training on administration of instruments, safety, and etiquette. While in the home, interviewers read the questions for all parents, collected measures, and recorded responses by hand.

In addition, the researcher-developed protocol was audio taped for accuracy and coding purposes.

Measures

Questionnaires and the interview protocol utilized in the study yielded both quantitative and qualitative data. As mentioned previously, a mixed method approach was utilized in order to more accurately answer the posed research questions and gain a deeper understanding of the impact of raising a child with HFA/AS which could not necessarily have been achieved through the use of only paper and pencil measures.

Family Information Form (FIF): A brief questionnaire was administered to parents to collect demographic information such as child's gender and ethnicity, parent marital status, mother and father's age, education, job description, income category, and employment status [51].

Family Impact Questionnaire (FIQ): The Family Impact Questionnaire is a 50-item Likert-type questionnaire assessing the perceived impact that a child has on the family relative to the impact that other children have on their families. The FIQ yields six scale scores that measure Negative Impact on Parenting, Social Relationships, Finances, Marriage, Siblings, and Positive Impact on Parenting. A sample item pertaining to negative impact is: (compared with children the same age as my child) 'My child's behavior embarrasses me in public more.' Response options are 0 (Not at all), 1 (Somewhat), 2 (Much), and 3 (Very much). A sample item pertaining to positive impact is: (compared with children the same

Table 1: Characteristics of the Sample.

Variable	Percentage
Child (n = 15):	
Age (mean)	8
% Male	83.3
% Caucasian	83.3
% Hispanic	11.1
CBCL Scores	
% with clinical externalizing 33.3 behaviors	33.3
% with clinical internalizing 46.6 behaviors	46.6
Mother	
Age (mean)	40.1
% Employed	50.0
% with B.A. or >	44.4
Father	
Age (mean)	45.7
% Employed	93.3
% with B.A. or >	46.7
Other: Income	
\$0-15,000	6.7
\$35,001-50,000	6.7
\$50,001-95,000	20.0
\$>95,000	66.7
% Married	86.7

age as my child) 'My child makes me feel more confident as a parent.' The positive impact subscale utilizes the same response options as the Negative Impact subscale. In the present study, we utilized all six FIQ subscale scores. Scale reliabilities range from $r = .83$ to $.92$ [52].

Child Behavior Checklist for ages 4-18 parent (CBCL): The CBCL is a 118-item measure given for students aged between 4-18 years. Parents completed the CBCL in order to determine their rating of child behavior problems. Behaviors or problems are listed and participants rate each item on a 3-point Likert-type scale: not true (0), somewhat or sometimes true (1), or very true or often true (2). A T-score with a mean of 50 and standard deviation of 10 is derived for total behavior problems, with a higher score being indicative of more behavior problems. Reliability for behavior problems is $.84$ and for social competencies $.97$. According to the CBCL manual, the criterion-related validity is widely supported through multiple regressions, relative risk odd ratios, and discriminant analyses. The CBCL is highly correlated with other instruments such as the Conner's Rating Scales and Behavior Assessment System for Children (BASC). The Internalizing and Externalizing T-scores were used in the current study [53].

Researcher developed interview protocol: The guided interview protocol consisted of 32 closed or open-ended questions, specifically designed for this study, examining family and child issues related to raising a child with HFA/AS. Domains discussed included diagnosis (e.g. initial concerns and diagnostic process), impact on family (e.g. effects on daily routines, siblings, and parents), obtaining services (e.g. types of services/interventions received and stress and cost of obtaining current and previous services), and future perspectives (e.g. future educational, employment, and living situation). Closed ended questions consisted of dichotomous (yes/no) and Likert scale items (1-5). Sample dichotomous items included: Was the diagnosis you received agreed upon? Are you or a member of your family a member of, or involved in, any parent/professional organizations for families of children with autism? Are there any particular routines or aspects of family life that are affected by your child's AS/HFA? Did your child receive any services prior to diagnosis? The Likert scale items were rated on a 5-point scale (5=completely satisfied, 1=completely dissatisfied) and included questions such as: How satisfied were you with the diagnostic process? And how satisfied are you with your child's current school program? Open ended questions asked specifically about each domain and included: What was the first concern you had about your child? How has having a child with HFA/AS affected your life? Please describe your child's current educational program. What do you think about most as you consider your child's future? For the interview, both mothers and fathers were respondents. Participation in the interview was as follows: 33.3% of mothers responded alone, 5.6% of fathers responded alone, and 61.1% of the participants responded together.

The two staff members present during the parent interview was responsible for coding the researcher developed interviewer protocol. This process included reading responses to obtain a sense of the content, extracting relevant statements within each open-ended question response, and creating shared themes from extracted statements (e.g. first concerns; language development, developmental delay, social development, restrictive play, etc.) within each section

of the protocol (diagnosis, impact on family, obtaining services, and future perspectives). Quotes were then taken from each identified theme area to be included in the current paper. Inter rater reliability for developing shared themes with each section was 91%. All procedures were approved by the Institutional Review Board of the university.

Results

Based on the overarching themes framed in the researcher developed protocol, results are discussed in terms of diagnosis (e.g. initial concerns and diagnostic process), impact on family (e.g. effects on daily routines, siblings, and parents), obtaining services (e.g. types of services/interventions received and stress and cost of obtaining current and previous services), and future perspectives (e.g. future educational, employment, and living situation).

Diagnosis

Themes surrounding the topic of diagnosis included initial parental concerns, professional assistance, and concerns upon receiving a diagnosis. Child characteristics that were initially concerning to parents leading them to seek a professional diagnosis included social skill deficits, language delays, repetitive behaviors, and behavior problems. All children in this sample were diagnosed between the ages of two and four with a mean age of 3.9 years. Forty-four percent of parents reported social skill deficits in their children including inappropriate to play, isolated play, and inability to interact with other children. Language delays were reported by 81% of parents and included echolalia and overall language delays. Obvious repetitive behaviors such as hand flapping, lining up toys/items, and rocking were reported by 20% of families. Surprisingly, only 27% of families noted their child's behavior problems as the catalyst for seeking an initial diagnosis.

During the diagnostic process, 60% of families were told by a pediatrician that their child had a speech delay and 19% were told that there was nothing to worry about because boys developed more slowly. Only 13% were told initially that their child might have autism. One caregiver commented, "Most pediatricians don't know anything about autism. I was told he had a speech delay and his social skills would catch up with his speech." Another said, "We weren't paying attention and we kick ourselves for that. We should have seen it but the doctors said nothing."

When seeking a diagnosis, parents had varying experiences. When asked to rate their satisfaction with the diagnostic process on a five point scale, ranging from completely dissatisfied to completely satisfied, 60% of families were dissatisfied with the process. In each of these cases, parents reported that the process of getting a diagnosis took too long and valuable time was lost when their child could have been receiving intervention. Conversely, 34% of parents were satisfied with the process and 6% were indifferent.

Obtaining services

Parents reported information about obtaining services, including their overall satisfaction, amount of stress experienced, current level of services being provided, and type of agencies providing services. Overall, 94% of parents reported that the process of obtaining services was a bit or extremely stressful. One parent stated, "The

services you want no one will provide, but the ones that don't work they try to cram down your throat." Another parent said, "The most stressful aspect is the hostility of people actively trying to keep you from getting services." Many parents believed (33%) they did not have enough knowledge of the services available to their child, which caused them additional stress.

Although the majority of parents found the process of obtaining services stressful, 66.7% were satisfied or completely satisfied with the current educational programming their child was receiving. Services students were receiving included speech (73.3%), applied behavior analysis (33.3%), occupational therapy (26.7%), adapted physical education (26.7%), one-to-one classroom support (26.7%), social skills training (13.3%), mental health services (13.3%), and physical therapy (6.7%). With the exception of applied behavior analysis services, which were provided 50% by the school district and 50% by outside agencies, all other services were provided by the public school systems attended by the children.

Recommendations on diagnostic and professional services

During the interview, parents were asked to reflect on the diagnostic process and on obtaining services, in order to determine what would have been most helpful to them during that time. Sixty percent of parents stated that they wish they had received a diagnosis earlier. An instruction guide for parents to assist in the diagnostic process, obtaining services, and understanding autism was also mentioned by 27% of the parents as an area of need. Parents also opined about overall support (13%). One parent stated, "I wish someone would have helped me. We need well organized and appropriate information for parents." In addition, parents needed help with educational placement for their children (26%) and funding for services (7%). All parents were able to obtain information about autism on the Internet, including those without a computer in their home, but found that navigating the system and sorting out the overwhelming amount of information on autism and Asperger syndrome was difficult.

Much of the information parents provided, in terms of what would have been most helpful to them during the early stages of diagnosis and service delivery, was also reflected in the information regarding the role of professionals. Parents were asked what professionals could do now to help them and other families like them. Parents expressed that training more professionals about autism (33.3%) and improving the process of obtaining services were most important (33.3%). They also mentioned providing more information to parents as a necessity (26.7%), rather than as a response to parents' multiple requests. In addition, increasing public knowledge and awareness (20%) as well as providing earlier and more effective treatment (20%) was important to these families of children with HFA/AS.

Family impact

Throughout the interview process parents reported positive and negative impact of their child on themselves and on their families. In terms of their lives in general, 93.3% of parents reported concerns about their children with behavior challenges and about changes these brought to the daily family routine. Upon examining the CBCL, 33% of the children rated were within the clinical range for externalizing behaviors and 46% were in the clinical range for internalizing

behaviors (information can also be seen in Table 1). One parent reported, "You have to be 'on' all the time. It's hard to relax." Other specific effects on the family routine included working around the child's schedule (53.3%), constant work involving the child (53.3%), no time for themselves (53.3%), fewer social activities (40%), having special diets and medication (33.3%), and a lack of friends and a social life (20%). In addition, parents also reported an overall negative impact on their marriage (20%). One parent stated, "Caring for a child with HFA/AS is physically demanding, mentally demanding, and time consuming." There were also reports of sibling negative impact including other siblings receiving less attention (26.7%), the target child's behavior interfering with family activities (13.3%), and the time commitment involved in the child's therapy (13.3%).

Although these families reported some negative impact, positive impact was noted as well. Eighty-seven percent of families reported that they now appreciated the little things in life and 55.6% appreciated their child's accomplishments and progress. Although most parents reported some positive family and life impacts, 13.3% of families were unable to think of anything positive to say.

The information gathered during the interview was supported by the correlations found between the CBCL and FIQ. The relationship between problem behaviors and family impact was examined by correlating broadband CBCL scores with FIQ subscale scores. As seen in Table 2, internalizing scores were not found to relate to any of the six FIQ subscale scores. Externalizing scores, however, positively related to social life, negative feelings about parenting, and marital impact.

Future perspectives

Parents of children with autism have previously reported concerns that might affect the future of their child, such as achievement, self-esteem, coping, learning difficulty, and fears of bullying [27]. Parents' in this current study offered comments that mirrored some of these same concerns as well as others. Worries about the child's future social development (46.7%) were salient for this sample of parents, with one parent stating, "If your kid is typical you want him to stand out, but if he is not you want him to blend in." Parents were also concerned about their child becoming independent (40%) and equally concerned about overall safety and future service provisions (26.7%). Other concerns about the days ahead included future educational placement and service options (13.3%), as well as job skills and employment (6.7%).

Discussion

The primary aim of this study was to investigate family experiences

Table 2: Parent CBCL Scores Correlated with FIQ Subscales.

FIQ Subscales	Child Behavior Checklist	
	Externalizing	Internalizing
Social	.69**	.34
Negative Feelings	.66**	.39
Positive Feelings	-.01	.31
Marriage	.61*	-.17
Finances	-.39	-.25
Siblings	-.45	.40

** $p < .01$

pertaining to a specific population of children with ASD: children with HFA and AS. The diagnostic process, obtaining services, family impact, and parents' future concerns for their children were examined through parent interviews and parent-completed measures. The findings of this study contributed to the literature by ascertaining the unique experience of families raising children with HFA/AS in early elementary school with HFA and AS. The investigation utilized qualitative and quantitative reports that allowed a breadth of investigation.

Diagnostic process

Pursuing a diagnosis for their child is often parents' inaugural interaction with the field of autism. Due to the fact that ASD is not simply confirmed through a blood test, but rather observations and ratings of atypical behaviors, parents may encounter increased stress and anxiety in trying to secure a correct diagnosis and related interventions. In fact, the majority of participants in this investigation indicated that their children received an incorrect diagnosis from a pediatrician and only 13% of children with HFA/AS in this study received a correct initial diagnosis. Misdiagnoses were predominately labeled as language delayed. Unfortunately, despite clinicians' growing knowledge on the diagnosis and treatment of ASD, current research highlighted problems in obtaining a diagnosis may be related to a child's initial relationship with his or her pediatrician, who is usually the first professional that parents approach with their concerns. One recent study described pediatricians' self-reported lack of education on ASD and their low interest in pursuing further knowledge about ASD [54]. An additional complicating factor in diagnosis was the lack of early ASD screenings despite the American Academy of Pediatrics policy statement recommending that physicians screen for ASD twice before a child's second birthday. When parents in this study noted their concerns to the pediatrician, parent reports indicated that their pediatricians employed the "wait and see" model. For example, one parent reported her doctor as telling her, "Don't worry about it!" Parents also described a "feeling of panic" that valuable time was lost in making gains with evidence-based interventions while diagnostic problems were sorted out. Based on their experiences, about one-fourth of the parent participants commented that trainings for medical professionals were necessary to improve diagnostic accuracy and appropriate recommendations for intervention. These findings seem striking in light of early screening mandates and the increased rates of ASD.

Obtaining services

When the process of obtaining services was investigated, families indicated they felt a great amount of stress making important intervention decisions based on receiving very little information. In regard to treatment decisions, scientific research in the field of autism has provided extensive reviews in identifying best practices for educating children with autism [55,56]. For instance, Applied Behavior Analysis (ABA) has emerged as an evidence-based practice [57,58] aimed to improve socially significant behavior such as communication and social skills. Despite what is known about ABA as a successful intervention for autism, almost two-thirds of the sample was not receiving ABA services. Furthermore, only 13% of participants indicated that their children received specific supports to increase their child's social skills even though social interaction is described as a core central deficit with implications for successful

long-term functioning [59]. Corroborating reports from other investigations indicated that 74% to 92% of children with ASD were not enrolled in empirically validated programs [60,61]. According to the current study, parents' self-described lack of education regarding autism interventions may have hindered their ability to advocate for evidence-based treatment decisions. Educating parents on how to evaluate the efficacy of their child's intervention may increase involvement in evidence-based interventions targeting specific areas of deficit [62,63].

Although parents reported initial frustrations over obtaining services, with one parent comparing it to "a hard battle", the majority of participants expressed satisfaction with current supports their children were receiving. In light of the low rate of social skills and ABA services being administered, this finding may again reflect the need for parent training and education on evidence-based intervention services. Indeed, over one-fourth of participants indicated their need for more education with comments such as "I wish someone would have helped me...we need well organized appropriate information for parents." Too, often public school districts do not see the offering of ABA services and social skills as priorities for children with HFA/AS.

Behavior and family impact

One troubling finding in the investigation on family experiences and HFA/AS was the contribution of maladaptive behaviors to negative family impact. While this finding is not surprising in light of prior research on behavior problems and stress, [64-66], it was interesting that those findings held true when family impact of children on the high functioning end of the autism spectrum were investigated. The impact of externalizing behaviors is widely felt as our analysis showed it related to multiple facets of family functioning. Specifically, parent ratings of high externalizing behaviors were significantly associated with lower quality social experiences. A prior investigation focusing on children with autistic-like characteristics found similar results in that parents experienced lower quality of life and fewer social relationships than did parents of children with cerebral palsy or mental retardation [67]. In this particular investigation, not only did externalizing behaviors impact social life, but the "routine of autism" was related as well. The day-to-day management of having a child with HFA/AS contributed to fewer social activities and less time for the parents' to spend in their own social activities. Parent comments indicating that they were always "on a schedule" and "constantly focused" on their child underscores the need for respite supports. These findings were mirrored in a previous study concluding that parents of children with autism had high levels of stress, but had low access to recreation and leisure activities for themselves [49]. Again, the experiences of parents' with pre-adolescent children with HFA/AS were similar to those of study outcomes investigating families across the autism spectrum. Further compounding the stress of parents navigating HFA/AS was the lack of support from extended family members. Participants shared statements indicating that families "cannot fully understand from a verbal description" or "... don't even care to learn" about the challenges participants experience related to HFA/AS. Clearly, parents of children with HFA/AS report feeling challenged and stressed, and accessing age-appropriate evidence-based supports coupled with extended family backing may go far in alleviating burdens.

In addition to impacting parents' social life, higher externalizing behaviors were related to more negative feelings about parenting. In fact, 13% of participants were unable to think of anything positive to say about parenting a child with HFA/AS, with one parent voicing her experiences as "physically and mentally demanding and time consuming." This finding corroborates the experience of families across the spectrum dealing with ASD where problem behaviors have negative family impact [35,68]. This impact also extended to marriage relationships as higher ratings of externalizing behavior were significantly related to lower quality marriage, as rated by participants. An earlier study also examined marital impact [32], but investigated families living with children across the autism spectrum, not isolating families with HFA/AS as this study did. Despite the different populations, these researchers found similar results. Relationship stressors for couples of children with ASD and couples with typically developing children were compared. Results indicated that higher intensity child behavior problems and lower ratings of marital satisfaction were found in the ASD parent group.

One interesting finding of this study that differed from previous investigations concerned the sibling relationship. While prior research indicated negative outcomes for typical siblings [69,70] this study found that the externalizing behaviors of siblings with HFA/AS were not significantly related to sibling impact. The ability of the siblings with HFA/AS to verbally communicate and the propensity for higher IQs may have acted as buffers between problem behaviors and negative sibling impact while earlier research included children across the autism spectrum who may have had intellectual disability and non-verbal communication found in individuals with moderate-severe autism. Future research would be well served to compare the sibling relationship among different levels of impairment of children with ASD (i.e. levels 1, 2, and 3) while controlling for externalizing behaviors. Although our investigation found parent-reported negative impact on a variety of family-related issues, the parent interviews also indicated that the majority of parents were able to articulate positive aspects of parenting a child with HFA/AS. Specific comments such as, "She's amazing," or "You appreciate the learning process and the little steps in life," paint a portrait of the benefits parents encounter from their children, despite the unique challenges they face.

Concerns for the future

While many families struggled through the diagnostic process, securing services, and maintaining their psychological health, they also had focus on their child's future, expressing concerns for their child's social development. One father indicated, "Hopefully I won't have a 12-year-old who is a social outcast." In light of the average to above average IQs of individuals with HFA/AS, worries over social interaction were warranted as these deficits often stand out and have future impact on employment, relationships, and mental health [22,24]. However, parents did not specifically articulate concern for those patterns of outcome in which adolescents and adults with HFA/AS are most vulnerable, rather social development in general. For example, parents did not articulate fears over the development of related mental health disorders, and only one parent mentioned concerns over employment by commenting that, "We don't expect him to be independent". One may surmise that increasing parent education may help parents anticipate long-term outcomes and assist

their children in developing the necessary skills to facilitate successful futures.

Summary and implications

Taking the above information as a whole, it seems clear that families of early elementary school aged children with HFA/AS need further attention in the research base. By narrowing the lens on a specific group of autism spectrum disorders, this investigation was able to examine the challenges uniquely associated with HFA/AS. In addition, the interview format of this study provided additional information that would not have been captured in a pencil and paper format. Parents were able to express their experiences freely through the semi-structured interview process and valuable information regarding parent and family experiences were captured. The fact that many couples participated in the interview process together was also a strong component of the study and provided additional information that would not have been captured by interviewing only one parent. Although the sample was small, and likely not representative of all parents of young children with HFA/AS living in the 21st century, there was consistency in their responses that begged further professional attention.

There are implications from the findings of this study for families and professionals. An important link between parent education and intervention was found. Many parents articulated the need for more information about the educational process for their children. Increased knowledge may empower parents to advocate for appropriate interventions for their children with HFA/AS and ensure that they are working toward goals that increase successful functioning into adulthood. Furthermore, despite recent policy statements from the American Association of Pediatrics advocating for improved autism screening practices, physicians would also benefit from increased and continued education on diagnosing and making recommendations for treating autism spectrum disorders, especially in children who are higher functioning and who may not obviously display the key deficits related to ASD. It seems that families of children with HFA/AS in this sample and prior studies of families with children across the autism spectrum encountered similar challenges. Accessing familial support, marital relationships, and participating in social and leisure activities were problematic. Families of children with HFA/AS not only encountered disability-related challenges, but they were also forced to navigate relationships with medical professionals, extended family members, and with each other.

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References

1. Freeman BJ, Cronin P, Candela P. Asperger syndrome or autistic disorder? Focus on Autism & Other Developmental Disabilities. 2002; 17: 145-151.

2. Ghaziuddin M, Mountain-Kimchi K. Defining the intellectual profile of Asperger syndrome: Comparison with high-functioning autism. *Journal of Autism & Developmental Disorders*. 2004; 34: 279-284.
3. Klin A, Pauls D, Schultz R, Volkmar F. Three diagnostic approaches to asperger syndrome: Implications for research. *Journal of Autism & Developmental Disorders*. 2005; 35: 221-234.
4. American Psychiatric Association. *Diagnostic and statistical manual of disorders*. Fifth edn. Washington, D.C.: American Psychiatric Association. 2013.
5. Van Roekel E, Scholte R, Didden R. Bullying among adolescents with autism spectrum disorders: Prevalence and perception. *Journal of Autism and Developmental Disorders*. 2010; 40: 63-73.
6. Attwood T. Framework for behavioral interventions. *Child and Adolescent Psychiatric Clinics of North America*. 2003; 12: 65-86.
7. Kim J, Szatmari P, Bryson S, Streiner D, Wilson F. The prevalence of anxiety and mood problems among children with autism and asperger syndrome. *Autism: The International Journal of Research & Practice*. 2000; 4: 117-132.
8. Barnhill G. Social attribution and depression in adolescents with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*. 2001; 16: 46-53.
9. Hedley D, Young R. Social comparison processes and depressive symptoms in children and adolescents with Asperger syndrome. *Autism*. 2006; 10: 139-153.
10. Vickerstaff S, Heriot S, Wong M, Lopes A, Dossetor D. Intellectual ability, self-perceived social competence, and depressive symptomatology in children with high-functioning autistic spectrum disorders. *Journal of Autism & Developmental Disorders*. 2007; 37: 1647-1664.
11. Butzer B, Konstantareas M. Depression, temperament and their relationship to other characteristics in children with asperger's disorder. *Journal on Developmental Disabilities*. 2003; 10: 67-72.
12. Ghaziuddin M, Alessi N. Life Events and Depression in Children with Pervasive Developmental Disorders. *Journal of Autism & Developmental Disorders*. 1995; 25: 495-502.
13. Ghaziuddin M, Greden J. Depression in children with autism/pervasive developmental disorders: A case-control family history study. *Journal of Autism & Developmental Disorders*. 1998; 28: 111-115.
14. Barnhill G, Myles B. Attributional style and depression in adolescents with asperger syndrome. *Journal of Positive Behavior Interventions*. 2001; 3: 175-182.
15. Kanner L. Follow-up study of eleven autistic children originally reported in 1943. *Journal of Autism & Childhood Schizophrenia*. 1971; 1: 119-145.
16. Piven J, Harper J, Palmer P, Arndt S. Course of behavioral change in autism: A retrospective study of high-IQ adolescents and adults. *Journal of the American Academy of Child & Adolescent Psychiatry*. 1996; 35: 523-529.
17. Tantam D. Psychological disorder in adolescents and adults with Asperger syndrome. *Autism*. 2000; 4: 47-62.
18. Boelte S, Poustka F. Diagnosis of autism: The connection between current and historical information. *Autism: The International Journal of Research & Practice*. 2000; 4: 382-390.
19. Gilchrist A, Green J, Cox A, Burton D, Rutter M, Le Counter A. Development and current functioning in adolescents with asperger syndrome: A comparative study. *Journal of Child Psychology and Psychiatry*. 2001; 42: 227-240.
20. Gillberg C, Steffenburg S. Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders*. 1987; 17: 273-287.
21. Venter A, Lord C, Schopler E. A follow-up study of high-functioning autistic children. *Journal of Child Psychology & Psychiatry & Allied Disciplines*. 1992; 33: 489-507.
22. Seltzer M, Krauss M, Shattuck P, Orsmond G, Swe A, Lord C. The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism & Developmental Disorders*. 2003; 33: 565-581.
23. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *Journal of Child Psychology & Psychiatry*. 2004; 45: 212-229.
24. Howlin P, Mawhood L, Rutter M. Autism and developmental receptive language disorder--a follow-up comparison in early adult life. II: Social, behavioral, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry*. 2000; 41: 561-578.
25. Orsmond G, Krauss M, Seltzer M. Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism & Developmental Disorders*. 2004; 34: 245-256.
26. Muller E, Schuler A, Burton B, Yates G. Meeting the vocational support needs of individuals with asperger syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*. 2003; 18: 163-175.
27. Lee L, Harrington R, Louie B, Newschaffer C. Children with autism: Quality of life and parental concerns. *Journal of Autism & Developmental Disorders*. 2008; 38: 1147-1160.
28. Little L, Clark R. Wonders and worries of parenting a child with Asperger syndrome & nonverbal learning disorder. *Journal of Maternal Child Nursing*. 2006; 31: 39-44.
29. Shtayerman O. Peer victimization in adolescents and young adults diagnosed with Asperger's syndrome: A link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues in Comprehensive Pediatric Nursing*. 2007; 30: 87-107.
30. Keenan M, Dillenburger K, Doherty A, Byrne T, Gallagher S. The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*. 2010; 23: 390-397.
31. Dillenburger K, Keenan M, Doherty A, Byrne T, Gallagher S. Living with children diagnosed with autistic spectrum disorder: Parental and professional views. *British Journal of Special Education*. 2010; 37: 13-23.
32. Brobst J, Clopton J, Hendrick S. Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism & Other Developmental Disabilities*. 2009; 24: 38-49.
33. Kelly A, Garnett M, Attwood T, Peterson C. Autism spectrum symptomatology in children: The impact of family and peer relationships. *Journal of Abnormal Child Psychology*. 2008; 36: 1069-1081.
34. Abbeduto L, Seltzer M, Shattuck P, Krauss M, Orsmond G, Murphy MM. Psychological well being and coping in mothers of youths with autism, Down syndrome, or fragile x syndrome. *American Journal on Mental Retardation*. 2004; 109: 237-254.
35. Blacher J, McIntyre L. Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*. 2006; 50: 184-198.
36. Eisenhower A, Baker B, Blacher J. Preschool children with intellectual disability: Syndrome specificity, behavior problems, and maternal well-being. *Journal of Intellectual Disability Research*. 2005; 49: 9 657-671.
37. Noh S, Dumas J, Wolf L, Fisman S. Delineating sources of stress in parents of exceptional children. *Family Relations*. 1989; 38: 456-461.
38. Seltzer M, Krauss M, Tsunematsu N. Adults with Down syndrome and their aging mothers: Diagnostic group differences. *American Journal on Mental Retardation*. 1993; 97: 496-508.
39. Wolf L, Noh S, Fisman S, Speechley M. Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*. 1989; 19: 157-166.
40. Herring S, Gray K, Taffe J, Tonge B, Sweeney D, Einfield S. Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*. 2006; 50: 874-882.
41. Smith L, Hong J, Seltzer M, Greenberg J, Almeida D, Bishop S. Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders*. 2010; 40: 167-178.

42. Hartley SL, Barker ET, Seltzer M, Greenberg J, Bolt D, Floyd F, et al. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*. 2010; 24: 449-457.
43. Dunn M, Burbine T, Bowers C, Tantleff-Dunn S. Moderators of stress in parents of children with autism. *Community Mental Health Journal*. 2001; 37: 39-52.
44. Mackintosh V, Myers B, Goin-Kochel R. Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*. 2005; 12: 41-52.
45. Lee G, Lopata C, Volker M, Thomeer M, Nida R, Toomey JA, et al. Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*. 2009; 24: 227-239.
46. Heiman T, Berger O. Parents of children with Asperger syndrome or with learning disabilities: Family environment and social support. *Research in Developmental Disabilities: A Multidisciplinary Journal*. 2008; 29: 289-300.
47. Altieri M, Von Kluge S. Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies*. 2009; 18: 83-92.
48. Chan J, Sigafos J. Does respite care reduce parental stress in families with developmentally disabled children? *Child & Youth Care Forum*. 2001; 30: 253-263.
49. Sanders J, Morgan S. Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child & Family Behavior Therapy*. 1997; 19: 15-32.
50. Green JC, Caracelli VJ. editors. In: *Advances in mixed-method evaluation: The challenges and benefits of integrating diverse paradigms New Directions for Evaluation*, No. 74 San Francisco: Jossey-Bass. 1997.
51. Baker BL, Blacher J, Crnic K, Edelbrock C. Behavior problems and parenting stress in families of three year old children with and without developmental delays. *American Journal of Mental Retardation*. 2002; 107: 433-444.
52. Donenberg G, Baker BL. The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*. 1993; 21: 179-198.
53. Achenbach TM. *Manual for the CBCL 4-18*. Burlington, VT: University of Vermont. 2000.
54. Finke EH, Drager K, Ash S. Pediatricians' and parents' perspectives on the diagnostic process for autism spectrum disorders. *Journal of Early Childhood Research*. 2010; 8: 254-268.
55. Odom SL, Collet-Klingenberg L, Rogers SJ, Hatton DD. Evidence-based practices in interventions for children and youth with autism spectrum disorders. *Preventing School Failure*. 2010; 54, 275-282.
56. Simpson R. Evidence-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*. 2005; 20: 140-149.
57. National Research Council. *Educating children with autism*. Washington, DC: The National Academies Press. 2001.
58. Rogers SJ, Vismara LA. Evidence-Based Comprehensive Treatments for Early Autism. *Journal of Clinical Child & Adolescent Psychology*. 2008; 37: 8-38.
59. Klin A, Volkmar FR. Asperger's syndrome. D. J. Cohen & F. R. Volkmar, editors. In: *Handbook of Autism and Pervasive Developmental Disorders*. 3rd edn. New York: Wiley & Sons. 2005; 94-122.
60. Hanson E, Kalish L, Bunce E, Curtis C, McDaniel S, Ware J, et al. Use of complementary and alternative medicine among children diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2007; 37: 628-636.
61. Harrington JW, Rosen L, Garnecho A, Patrick PA. *Journal of Developmental & Behavioral Pediatrics*. 2006; 27: 156-161.
62. Kay S, Vyse S. Helping parents separate the wheat from the chaff: Putting autism treatments to the test. Jacobson JW, Foxx RM, Mulick JA, editors. In: *Controversial therapies for developmental disabilities*. 2005; 265-277.
63. Smith T, Antolovich M. Parental perceptions of supplemental interventions received by young children with autism in intensive behavior analytic treatment. *Behavioral Interventions*. 2000; 15, 83-97.
64. Allik H, Larsson J, Smedje H. Insomnia in school-age children with Asperger syndrome or high-functioning autism. *BMC Psychiatry*. 2006; 6: 18-29.
65. Hastings RP. Brief report: Behavioral adjustment of siblings if children with autism. *Journal of Autism and Developmental Disorders*. 2003; 33: 99-104.
66. Tomanik S, Harris G, Hawkins J. The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual & Developmental Disabilities*. 2004; 29: 16-26.
67. Mungo D, Ruta L, D'Arrigo V, Mazzone L. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*. 2007; 5: 5-22.
68. Hastings R, Kovshoff H, Brown T, Ward N, Espinosa F, Remington B. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*. 2005; 9: 377-391.
69. Hastings RP. Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*. 2007; 37: 1485-1492.
70. Ross P, Cuskelly M. Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability*. 2006; 31: 77-86.