

Financial Issues Associated with Having a Child with Autism

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Abstract Data from the Family Experiences with Autism Survey are used to identify factors associated with financial problems in families that have a child with autism. Likelihood of financial problems was positively associated with use of medical interventions, having unreimbursed medical or therapy expenses, and having relatively lower income. Use of speech and language therapy was negatively associated with likelihood of financial problems. Many survey respondents forfeited future financial security and even experienced bankruptcy to provide needed therapy for a child with autism. Specific ways that financial advisors can help families that have a child with autism are outlined.

Keywords Autism · Caregiving · Financial burden · Special needs planning

Introduction

Autism is a diagnosis no parent wants to hear. As any family that has a child with autism can attest, receiving that diagnosis begins a journey that places profound demands on family human and financial resources for the remaining lifetime of the child (Schall, 2000).

Autism is a biologically based developmental disorder that impairs an individual's ability to communicate, build relationships, and relate appropriately to the environment. Diagnosis is usually made in early childhood after a multi-disciplinary

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assessment of behavior, developmental level, and communication ability (Autism Society of America [ASA], 2004c).

Fifteen years ago, the incidence of autism was 1–2 per 10,000 in the United States. Now, the incidence rate is 2–6 per 1,000 or between 1/500 and 1/166; 50 families a day hear their child has autism (Betts, 2005; Centers for Disease Control, 2005). Over the past decade, the U.S. population has grown about 13%; non-autism related disabilities have increased around 16%, while the recorded incidence of Autism Spectrum Disorders has risen 173% (Betts, 2005). Today, one in four Americans knows someone with autism; most frequently a family member (Autism Today, n.d.). A 10–17% annual growth rate for autism is projected (ASA, 2004c).

Reasons for the sudden and insistent surge in incidence of autism are hotly debated; no consensus regarding cause exists (Fombonne, 2003b). Evidence is mounting, however, that behavioral and other therapeutic intervention early in the life of a child with autism is critical for improving communication, forming relationships, decreasing maladaptive behavior and developing independence (Larsson, 2005). Efficacy of early intervention depends on several factors, not the least of which is the specific nature and severity of autism.

Intervention strategies are expensive. Many strategies require long hours of one-on-one interaction with a trained therapist or use of costly foods or drug supplements. Health insurance falls far short of covering these needs. As of March 2006 17 states have mandated that insurers provide some level of autism coverage. Despite these mandates, the majority of costs are not covered (Sheinin, 2006). Making matters worse, there is recent evidence that *health shocks* such as autism increase the risk of loss of health insurance over time (Tseng, 2005). Special education services do not fill the gap either. Although public school districts are legally obligated to provide a *fair and appropriate education* to children with autism, the educational programs that are provided are rarely sufficient to address the needs of school-aged children with autism and are not available to young adults with autism. Thus, despite high costs, most parents feel compelled to seek out and try early intervention strategies for the sake of their child's future.

Costs associated with having a child with autism are not, however, limited to the cost of interventions. As is the case with many other forms of childhood disability, parents of a child with autism often face greater outlays of time and money than they would for a neurologically typical child. For example, specialized childcare is costly and often such care must be purchased for a longer period of time than a neurologically typical child would need. Additional cost is also associated with extracurricular activities for children with disabilities. One or both parents often must reduce work hours or step out of the labor market altogether (Gould, 2004). Though some assert that there may be financial *benefits* of having a child with disability such as saving the cost of forgone family vacations (Järbrink, Fombonne, & Knapp, 2003), such *savings* are likely to be much smaller than the additional costs.

Although much research effort has been given to autism's cause and treatment, aside from anecdotal accounts in the media or pilot studies with fewer than 25 participants (Järbrink et al., 2003) remarkably little attention has focused on the financial issues faced by families that have a child with autism. To address this gap in the literature, quantitative and qualitative data from the Family Experiences with Autism Survey are used in this study to investigate factors associated with financial problems in families that have a child with autism.

Background

Autism is a complex neurological disorder. To understand the reasons for and extent to which having a child with autism can affect family finances, it is helpful to review the characteristics of the disorder, the recorded rise in its incidence, the efficacy of different types of early intervention therapies and the financial burdens families that have a young child with autism shoulder despite federal law first enacted in 1975 that guarantees a fair and appropriate education for all children with a disability (Silverstein, 2005).

What is Autism?

Autism is a lifelong developmental disability resulting from abnormal brain function. The term *autism* comes from the Greek word *autos* meaning *self*. Leo Kanner (1943) used the term in 1943 to describe children who had profound impairment in communication and social skills, engaging in behavior that made them appear to withdraw into their own world.

Understanding of autism and related disorders has evolved over time. Autism is now recognized as a spectral disorder. The terms *autism* and *autism spectral disorder* (or *ASD*) are often used interchangeably to refer to three of five disorders that come under the broader category of Pervasive Developmental Disorders (PDD): Autistic Disorder, Asperger's syndrome, and Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS). The other two PDDs, Rett's Disorder and Child Disintegrative Disorder, are less common and manifest substantially differently than autism. The *Diagnostic & Statistical Manual of Mental Disorders* (DSM-IV-TR) of the American Psychiatric Association (APA) specifies diagnostic criteria for these five disorders (ASA, 2004c).

All those on the autism spectrum will, to a greater or lesser degree, experience developmental disability that is significant enough to impair daily life and social relationships. Language and communication skills, ability to relate to their environment and others, and ability to use imagination or abstract thought will be delayed or absent. At the same time, no two people with an Autism Spectral Disorder will act alike or have the same skill set. At the low functioning end of the spectrum is *classic autism* or *Kanner's autism*. Persons at this end of the spectrum may have little to no speech, resist change in routine, engage in ritualistic behavior such as hand flapping, rocking or spinning. Some are mentally retarded as well. At the other end of the spectrum, individuals with High Functioning Autism meet the criteria for diagnosis of autism, but are less severely affected. Those with Asperger's Syndrome are usually of normal or above normal intelligence, have age appropriate speech development but are seriously impaired in ability to communicate (language pragmatics). PDD-NOS characterizes a person who exhibits characteristics of autism or Asperger's Syndrome, but not of sufficient number or severity to be diagnosed in either category (Autism Victoria, 2005).

Why is Autism on the Rise?

While it is agreed that differences in the early development of the brain and central nervous system cause autism, reasons for this neurological difference are not so clear

and are hotly debated (University of Michigan Health Systems [UMHS], 2005). Theories have ranged from mercury in vaccines; revisions in diagnostic criteria over time; improvement in trained observation by educators and health care professionals; increase in environmental pollution; mate selection; and the relationship between diagnosis and access to services (Fombonne, 2003a). Changes in data, measurement, and definitions over time call for exercise of caution when computing change rates in autism incidence (Fombonne, 2001). Most estimates of autism incidence reported today come from referral statistics gathered by the U.S. Department of Education and other government agencies (ASA, 2004c).

A 1995 National Institutes of Health research team meeting concluded that autism is most likely the result of a genetic susceptibility. Research continues to identify which genetic, immunological, infectious, or environmental agents might contribute to presence of an autism spectral disorder at birth or prompt its development early in life (UMHS, 2005).

Autism is found worldwide; its incidence and growth rate appears consistent around the globe. It is found among families of all racial and ethnic backgrounds, and levels of socioeconomic status. Boys are four times as likely as girls to have an Autism Spectral Disorder (ASA, 2004c).

Importance of Early Interventions

There is no single, universally accepted treatment for autism. No cure exists for this lifelong condition. Indeed, some higher functioning adults with autism protest the notion of *cure* on the grounds that society has a responsibility to accommodate neurodiversity. Given current social conditions, however, the large part of the burden of accommodation rests on the individual with autism and his/her family. Consequently, most parents of a child with autism focus considerable resources on trying to maximize the potential their child has for integration into the dominant culture.

Achieving integration almost always requires some kind of deliberate intervention, but no guidelines exist regarding which treatment option is best. The number of treatment options currently available can generate frustration and confusion as well as hope for families seeking help for a child with autism. Efficacy of some treatments is supported by scientific studies, while other treatments may be experimental and have only anecdotal evidence of any beneficial results (ASA, 2004c). A comprehensive comparison of the success of different interventions has yet to be completed (Marcus, Rubin, & Rubin, 2000). Existence of a variety of therapies and interventions currently used by families that have a child with autism complicates estimating the costs associated with autism (Järbrink et al., 2003).

Research indicates that the earlier treatment begins the greater the chance for improvement if the intervention is comprehensive, intensive, individualized, extended over time and delivered directly to the child (Bryson, Rogers, & Fombonne, 2003; Guralnick, 1998). The first few years of a child's life is the optimal time to begin treatment, while the child's brain and social understanding is still developing.

Autism treatment has four broad categories. *Behavioral interventions* utilize discrete trial training where a child is asked to perform a specific action and responds. The therapist reacts with reward (usually praise) or correction. Backed by

research, Applied Behavioral Analysis (ABA) is the most widely recommended and utilized behavioral intervention. It is quite intense, requiring children to work one-on-one with a trained therapist for 30–40 h per week. It is expensive—up to \$30,000 per year. It aims to correct maladaptive or injurious behavior and teach life skills. Detractors criticize its invasion of family life, intensity, and cost. They also see it as reshaping the child's original personality, a goal they do not like. Supporters point to measured improvement in behavior and learning.

ABA is not the only behavior-based intervention for autism currently available; another is Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), a structured teaching approach that strives to adapt environment to a child's functional level. This intervention, which was first developed by Eric Schopler during the 1970s, seeks to build on the existing strategies and interests of the individual with autism (ASA, 2004c). Unlike ABA therapy, TEACCH explicitly accepts a *culture of autism* that maintains “people with autism are part of a distinctive group with common characteristics that are different, but not necessarily inferior, to the rest of us” (Mesibov, 2005). More recently, a new intervention called Relationship Development Intervention (RDI) has been developed.

Speech and language therapy helps a child with autism master the expressive and pragmatic language necessary for successful social interaction. This therapy and behavioral intervention are the prevalent therapies for young children with autism. Both are most frequently accredited with beneficial results, although they do not help all children with autism. Other therapies are somewhat experimental and less likely deemed helpful to any significant or consistent degree. Speech and language therapy is the predominate therapy available in public school system at no additional cost. Unlike behavior-based interventions, speech and language techniques used with children with autism are not necessarily uniquely developed for individuals with autism.

Neurosensory therapies such as sensory integration, over-stimulation and patterning, music therapy and supervised horseback riding are designed to help the child with autism integrate sensory experience, brain function, and response; overcome aversion to certain stimuli; and expand ability to adapt to sensory aspects of their environment (e.g., stay calm during a fire drill).

Biochemical interventions include treatment of food allergies, medication, food and vitamin supplementation. These interventions often involve doctors rather than educators, especially for dispensing prescription medication to manage behavior. Some families find diet and drug therapy helps reduce undesirable behavior and increase attention span, sometimes quite dramatically. Others do not.

Typically, professionals working with a child with autism will tailor treatments for that child and include more than one approach as no one treatment addresses all needs. Family members often try a variety of treatments, eventually stopping those that seem to have little benefit and retaining those that seem to be effective. Options for treatment also depend on what is available in a given community and what a family can afford.

Why the Financial Aspects of Autism Matter

A free and appropriate education for every child with a disability is guaranteed under the federal Individuals with Disabilities Education Act (IDEA). But, *appropriate* does not mean ideal, nor is it necessarily what parents believe is best for their child

(ASA, 2004a). Schools typically offer speech and language therapy, but districts simply cannot afford to pay the high cost of ABA therapy for each child with an autism diagnosis and, even if they could, they might not be able to hire the necessary personnel. Public schools are short more than 12,000 special education teachers, and the shortage is expected to rise as teachers retire or leave teaching (Tarkan, 2002).

Health insurance will sometimes cover the cost of medical tests used in the diagnostic process and the cost of prescription medication, but it will not pay for behavioral or other types of therapy for autism. The wait to participate in state or community funded therapy programs can be a year or more. As a result, parents desperate to find ways to help their child will pay thousands of dollars out-of-pocket or attempt to administer some therapies themselves.

Review of Literature

A literature review found only one study that dealt specifically with the financial impact of autism on the family. Järbrink et al. (2003) conducted a pilot study in the United Kingdom with 15 parents of a child with autism. Even with this small sample, they found the parents, on average, had weekly out-of-pocket costs equivalent to \$120 that were directly related to the education and care of their child with autism, costs that would not have been borne with a neurologically typical child.

A literature exists on the broader question of the economic cost of caring for a child with special needs, however. Relevant work from that literature is reviewed here.

Substantial attention has been given to women as caregivers across the lifespan (Marks, 1996, 1998), predominately focusing on 50- to 64-year-old women caring for frail elderly family members (Marks, 1996). Analysis of the financial, employment, psychological, and social consequences of caregiving has centered on this relatively older group (Aneshensel, Perline, & Schuler, 1993; Seltzer & Li, 2000). Recently, attention has turned to midlife women in atypical caregiving roles (Kahana, Biegel, & Wykle, 1994), including care of severely disabled children.

Leiter, Krauss, Anderson, and Wells (2004) used a 1997 data collection to investigate caregiving time and employment choices of women with severely disabled children under age 18. Almost 20% of the sample of 1,954 provided more than 20 h a week of non-routine care for a disabled—child—equivalent to part-time employment. Half of employed mothers had reduced work hours and half of not-employed mothers had quit work to better meet their child's needs. Most reported cutting back time for other children and household tasks.

Using data from the second wave of the 1995 California AFDC (Aid to Families with Dependent Children) Household Survey, Meyers, Lukemeyer, and Smeeding (1998) investigated the prevalence of childhood disability and chronic illness among families receiving welfare in California. Over 10% of low-income welfare recipient families cared for a severely disabled child or children with special needs. Mothers providing care for those children were less likely to be employed than mothers who did not have a severely disabled child. Among the very low-income group, tradeoffs were made between expenditures for the special needs child and basic living expenses and between care of child and other demands. They concluded that although relationships among disability, poverty, and welfare are complex, it does

appear that families caring for special needs children are at greater risk of experiencing poverty or material hardship. For these families, government programs such as Supplemental Security Income provide vital additional income support.

Childcare workers are not usually trained to meet the needs of special needs children, making it difficult for parents to find adequate care while they work. Fewell (1993) documented need for increase in such training and encouraged state agencies to utilize public funding to help parents afford daycare for special needs children so that they could be employed.

Using data from several states, Amo, Levine, and Memmott (1999) estimated that the national economic value of informal unpaid caregiving within families was almost \$200 billion in 1997, a figure substantially higher than the \$32 billion spent on formal home health care or the \$83 billion spent on nursing home care in the same year. They concluded that more effective ways must be developed to support family caregivers. A similar study conducted by the National Alliance for Caregiving and AARP (American Association of Retired Persons) in 2004 estimated the value of unpaid caregiving activities to be even higher at \$257 billion per year (Payndya, 2005).

In summary, literature focusing on the financial effects of care of special needs children indicates that caregiving time rivals part time employment and often precludes work outside the home. Time and money are often focused on the disabled child to the exclusion of the needs of other family members. Caregiving expenses are large. Federal programs help, but many families with special needs children still shoulder a large financial burden. Whether these same effects exist for families with children with autism is the focus of this research.

Method

Data

Data used in this research were from the Family Experiences with Autism survey. The survey was administered to 423 parents or primary caregivers of children with autism between July 2003 and May 2004. All study respondents were Midwest residents. Study participants were recruited using snowball sampling, postings on dedicated list serves, postings at doctor's offices, and direct mailings with the help of relevant non-profit and government agencies in the state. Use of existing personal and professional relationships tends to increase participation by the population of interest and is appropriate for obtaining data from rare groups, especially for exploratory research (Fulton, Samonte, Tierney, Conno, & Powell, 2001).

Survey respondents were asked (a) for their best estimate of autism-related expenses in the past year, (b) whether they had received publicly funded services in the last year, (c) if the family had had financial problems as a result of having a child with autism, and (d) what type of employment difficulties family members had experienced. Respondents were also given the opportunity to add open-ended comments relating to these questions. A limitation of these data, at least for this study, is that the original data collection focused heavily on public policy issues of having a child with autism. Some demographic information that would be useful for this study such as education level of the parent was not collected.

Sample

From the original set of 423 respondents, parents of a child under age 19 were selected for this study ($n = 333$). Parents were chosen to ensure financial impact questions referred to the household where the child with autism resided. Children with autism under age 19 were selected because high cost diagnostic and treatment services occur during early childhood years and older children could be residing outside the parental home.

Conceptual Framework

The Deacon and Firebaugh (1988) Family Resource Management Model offers two helpful perspectives to analyze the financial impact of having a child with autism. First, it conceptualizes the family as a dynamic system that interacts with a larger economic, social, and political system. Such systemic interaction is evident when autism generates need to work with various professionals and service providers to obtain diagnostic and treatment services. These services can force change in internal family behavior, while, at the same time, the specific needs and characteristics of a given family may require adaptation of type and timing of services.

Second, the input-throughput-output model of the family resource management process provides a framework for systematic analysis of the decisions and resource use of families who strive to provide their child with autism the best opportunity to succeed in a society that may not understand the limitations and challenges of autism. This model proposes that families secure, develop, and utilize resources to meet demands that take the form of value-based goals or unexpected occurrences that require a response (events). Applied to a family that has a child with autism, this model would imply that families utilize time and money resources to physically care for and educate their child who has autism, and equip their child to the extent possible with the means to operate as independent adults.

Another useful concept for understanding resource decisions of parents is separable and inseparable home production (Beutler & Owen, 1980). Separable home production is unpaid work at home that could be delegated to a paid worker. Inseparable home production is unpaid work that has characteristics that make it difficult to delegate to another. In caring for a child with autism, a parent may choose to purchase therapeutic services such as behavioral interventions that they could provide themselves given proper training (separable home production). Other caregiving services, however, a parent may not be willing or able to delegate to others, either because the market substitute would be prohibitively expensive or because personal involvement with the child is very important to the parent (inseparable home production). Closely monitoring effects of a dietary change over time or finding ways to include the child with autism in family activities would be examples of inseparable home production.

Empirical Analysis

Utilizing the conceptual framework and knowledge of the characteristics of autism and its diagnosis and treatment, the financial situation of families that have a child with autism can be viewed as the outcome of attempts to reconcile the demands of caring for a child with autism with available private and public resources.

Quantitative analysis is used to answer these questions:

- Are there significant differences in the characteristics of those who do and those who do not report having financial problems associated with caring for a child with autism?
- What statistically significant factors are associated with presence of financial problems in families that have a child with autism?

Chi square and *t*-tests are used to answer the first question. Given a dichotomous dependent variable, logistic regression is used to answer the second question.

Families reported reasons for the specific financial problems that they faced over the past year because of their child's autism. Qualitative analysis is used to identify broad themes across these responses and to draw some conclusions about the financial experience of families that have a child with autism.

Dependent Variable

The dependent variable for the logistic regression was coded 1 if respondent said *yes* to the question: "During the past twelve months, has your family had financial problems because of your child's autism or related conditions"?; 0, otherwise.

Independent Variables

Utilizing the conceptual framework that a family's managerial behavior is the result of reconciling demands with resources, child characteristics (child's age and limitation autism places on family activity), and unreimbursed out-of-pocket expenditures for various therapies, were considered demands on the family. Although it could be argued that intervention therapies are a human capital investment in a child with autism and so should be considered a resource, they are classified here as a demand because this study focuses on a family's existing financial issues and, at the time of the survey, final outcome of therapies used was not known. Family income level and receipt of public services were considered resources for the family.¹ Rural residence is included in the analysis since gaining access to services may be more difficult outside of urban areas.

Child Characteristics

Child's age was a continuous variable from 1 to 18. Responses of *yes* to the question, "Are your family's public or community activities restricted as a result of your child's autism or related condition?" were coded 1 for the variable *autism limits family activity*. This variable is a proxy for severity of the child's autism. It was expected that financial pressures would decrease with age as intense therapy ended but be more likely if a child was so low functioning as to require constant supervision, precluding parent employment.

¹ It could be argued that having more adults in a household is another resource, either for income-earning potential or caregiving. However, number of adults proved to not be a significant factor in the empirical model. It could also be argued that having more children in a home is related to financial difficulty separate and apart from autism. Preliminary analysis indicated that number of children in the home was highly correlated with variables of interest to the model. Thus, it was also omitted from the analysis.

Intervention Currently Utilized

Survey respondents were asked about current use of several prevalent therapies. These therapies included Applied Behavioral Analysis (ABA), speech and language therapy, sensory integration, diet modification, special education, music therapy, horseback riding therapy, and medical interventions (typically medications prescribed to address maladaptive behaviors or enhance attention span). Each was coded 1 if used, zero otherwise. Parents could indicate use of multiple therapies. Effect of these variables was thought to depend on cost, availability, and use. Of the group, ABA and medical interventions were expected to be the most expensive and most apt to be paid out-of-pocket.

Unreimbursed Out-of-pocket Expenditures

Survey respondents were asked “In the past twelve months, did you or your family have any OUT-OF-POCKET or DIRECT expenses for doctor’s visits or therapy related to autism, that were not reimbursed by any sources?” The question was repeated for prescription or non-prescription medication and for educational expenses. An affirmative answer was coded 1, 0 otherwise. Having such expenses was expected to adversely affect family financial situation.

Annual Household Income Level

Income was coded in categories that increased in \$10,000 increments up to \$60,000. The top category was \$60,000 and above. This top category was the reference category. Higher income households were expected to not experience financial difficulty.

Receive Public Services

“In the past twelve months, has your child received publicly funded services (such as special education) for his or her autism or related condition?” Responses of *yes* were coded 1, 0 otherwise. Public services are usually free, reducing pressure on family finances.

Rural Residence

This variable was coded 1 if true, 0 otherwise. Since access to therapies is much more common in urban areas, it was thought that rural residence might present a constraint or resource deficit for families.

Findings and Discussion

Comparison of Families That Did and Did Not Report Financial Problems

Comparison of means and proportions of various characteristics of those who did and who did not report having financial problems in the past 12 months due to autism are given in Table 1. These results indicate that, among those with financial

Table 1 Proportions and means of independent variables

Variables	Do not have financial problems ($n = 184$)	Have financial problems ($n = 149$)
<i>Child characteristics</i>		
Age	8.94 (3.96)	8.88 (4.04)
Autism limits family activity	0.66 (0.47)	0.91 (0.29)***
<i>Intervention currently utilized</i>		
ABA	0.41 (0.49)	0.47 (0.50)
Speech and language therapy	0.83 (0.37)	0.73 (0.44)*
Sensory Integration	0.50 (0.50)	0.55 (0.49)
Diet modification	0.22 (0.42)	0.32 (0.47)
Special education	0.78 (0.72)	0.68 (0.47)*
Music therapy	0.21 (0.41)	0.20 (0.40)
Riding therapy	0.07 (0.26)	0.11 (0.31)
Medical intervention	0.39 (0.49)	0.56 (0.49)**
<i>Unreimbursed out-of-pocket expenditures</i>		
Medical doctor/therapy	0.45 (0.50)	0.77 (0.42)***
Prescription or non-prescription drugs	0.39 (0.49)	0.61 (0.48)***
Education expenses	0.26 (0.44)	0.59 (0.49)***
<i>Economic resources</i>		
Annual household income level		
\$0 to \$10,000	0.05 (0.21)	0.05 (0.23)
\$10,001 to \$20,000	0.13 (0.33)	0.11 (0.31)
\$20,001 to \$30,000	0.10 (0.31)	0.15 (0.36)
\$30,001 to \$40,000	0.12 (0.32)	0.14 (0.36)
\$40,001 to \$50,000	0.10 (0.31)	0.11 (0.32)
\$50,001 to \$60,000	0.10 (0.31)	0.12 (0.33)
Over \$60,000	0.26 (0.44)	0.22 (0.42)
Receive public services	0.82 (0.38)	0.89 (0.32)
Rural residence	0.38 (0.48)	0.30 (0.46)

* $p < .05$; ** $p < .01$; *** $p < .001$

problems, a significantly higher proportion had autism limit family activities and had unreimbursed out-of-pocket expenses for doctor or therapy services, prescription and non-prescription drugs, and medical interventions. A significantly lower proportion had used speech and language therapy or special education. No significant difference was found between the two groups for child age, use of ABA, sensory integration, diet modification, music or riding therapy, income levels, receipt of public services, and rural residence, suggesting similar experience across all families in the sample for these items.

Factors Affecting Likelihood of Financial Problems

Results of the multivariate analysis of factors affecting likelihood of financial problems are presented in Table 2. Two results stand out. First, utilizing medical interventions and having unreimbursed out-of-pocket expenditures for medical doctor or therapy or for education expenses were significant factors in increasing the likelihood of financial problems (by 121, 264, 289%, respectively). Second, consistent with previous research and as expected, those with income under \$40,000 were more likely to have financial problems than those with incomes of \$60,000 or more. These results suggest that, especially for families with relatively lower income, demands of

Table 2 Factors associated with likelihood of financial problems in families that have a child under age 19 with autism

Variable	Parameter estimate (standard error)	Odds ratio
<i>Child characteristics</i>		
Age	-0.004 (0.036)	0.974
Autism limits family activity	1.064 (0.382)***	3.514
<i>Intervention currently utilized</i>		
ABA	-0.137 (0.287)	0.872
Speech and language therapy	-0.972 (0.384)*	0.378
Sensory Integration	0.040 (0.301)	1.041
Diet modification	0.023 (0.330)	0.977
Special education	-0.602 (0.347)	0.547
Music therapy	-0.218 (0.341)	0.804
Riding therapy	-0.235 (0.497)	0.791
Medical intervention	0.796 (0.306)**	2.216
<i>Unreimbursed out-of-pocket expenditures</i>		
Medical doctor/therapy	1.129 (0.355)***	3.647
Prescription or non-prescription drugs	-0.271 (0.343)	0.763
Education expenses	1.136 (0.293) ***	3.897
<i>Economic resources</i>		
Annual household income level		
\$0 to \$10,000	1.155 (0.646)*	4.699
\$10,001 to \$20,000	1.009 (0.494)*	2.744
\$20,001 to \$30,000	1.264 (0.462)**	3.541
\$30,001 to \$40,000	1.082 (0.462)*	2.947
\$40,001 to \$50,000	0.796 (0.483)	2.217
\$50,001 to \$60,000	0.233 (0.456)	1.263
Receive public services	0.388 (0.421)	1.474
Rural residence	-0.300 (0.295)	0.741
Intercept	-2.33 (0.69)	
-2 log likelihood	344.83	

* $p < .05$; ** $p < .01$; *** $p < .001$

autism diagnosis and treatment can seriously outstrip family resources. For at least low-income families, lawmakers should consider creating incentives for health insurance companies to cover some of these expenses or increase public funding for some of these costs.

Insight into Reasons for Financial Problems

Reasons given for financial problems by survey respondents give rare and poignant insight into the choices made by families that have a child with autism. Qualitative research techniques (Strauss & Corbin, 1998) were used to classify respondent report into several broad themes. Discussion and comment on some additional common experiences of families follows listing of the themes. To give voice to the families, some representative direct quotes are given for each theme (themes are in bold type).

Parents were painfully caught by the sharp edges of their suddenly changed world

Because of the constant battle with the special education director and the legal issues, I had to resign from my job...I LOST MY CAREER!!!! Now trying to

live off of student loans and homeschooling so that we can survive and hope to get my son back on track with his education.

Robbed future to pay for today—planning horizon was dramatically shortened from long term future to day to day

Cashed out my 401k from my former employer. Have sold all our stock. Taken out an equity line of credit on our house to pay for therapies.

Used up all our equity in our home and ... most of our retirement funds saved since we were married [in] 1984.

Choosing our child's welfare over family needs, paying for special diet foods, instead of bills, putting off bills to pay for supplements, etc.

Decreased ability to provide in future—life ins., retirement, trust for two kids with disabilities ... stopped contributing to a college fund for our sons and an IRA for me.

Autism's demands outstripped resources

We are struggling to meet our bills...My husband and I often do not eat lunch or dinner because we have no money left to buy food for ourselves ...We are hard pressed to make a choice between heat for our family and food.

Husband has taken on a second job to help make ends meet. Still, we live from paycheck to paycheck.

I had to quit my full-time job at \$40k/40 hrs wk—to take PT job at \$10k/20 hrs a week. This cut the family income in half. Our student loan debt has not been paid on since his diagnosis—2 yrs ago. Our general cash flow has been reduced so much that it is hard to pay bills on time every month. Our automobiles are getting old but we don't have good credit so could not buy a replacement at a decent % rate. We would love to refinance our home, but same story. My husband has a hard time getting 40 hrs. a week in at work due to issues with our son—resulting in reduced income again

Non-reimbursed therapies and equipment put strain on family budget. Other family members need counseling and medication to cope with the stress of living with autistic child. These costs further strain family budget.

Bankruptcy, once unthinkable, now seemed inevitable

We have maxed out our credit card and if it gets any worse are going to have to place our son in fostercare to have all his needs met or file for bankruptcy.

[We're facing] bankruptcy due to mounting medical bills not only involving our child but stress-induced illness and physical problems for parents

Family has been forced into bankruptcy—filed 3 months ago. Once a \$100,000/yr. family

Since Jan '03 when diagnosis of Autism was first given our family debt has grown by \$10,000. Bankruptcy is now a feasible option.

Family experience chronicles a sudden detour off a known paved road to an uncharted, rocky terrain that is fraught with unseen hazards in a vehicle running out of fuel and no additional resources in sight! Deep frustration, fear, and desperation permeate family comments. Watching their actions, it seems these families shifted the value placed on the future (their *future discount rate* in economic terms), from *saver* to *spender* in response to autism's demands. It also could be argued, however,

that these families are still future-oriented and still investing in the future but that future now takes the form of the life of their child with autism versus their 401k. Across responses, it was clear that obtaining therapy for a child with autism took precedence over all other family needs—even own basic needs as so poignantly noted by the parents who gave up their own meals to provide necessary therapy for their child with autism.

Specific causes given for financial difficulty varied. Some families cited their child's behavior. One parent noted the expense of replacing “2 broken windows, multiple VCR's, wall paper ... dresses, clothing, etc.” that had been destroyed by their child with autism. Others cited therapy cost: “ABA costs \$33,000 per year!” One battled an insurance company to “CONTINUE language therapy coverage.” Payment was refused for three months pending a final decision. Another remarked: “We have good medical insurance, but they do not cover all autism/Asperger's aspect of treatments.”

Several families write of major lifestyle changes after pulling a child out of what was perceived to be at best ineffective and at worst hostile public education system. Endless and bitter battles were enjoined with school districts to obtain the *fair and equal* education promised by federal law under IDEA. One family “spent over \$70,000 in due process costs and will probably spend over \$100,000 in the next year with school appeals.” The mother in another family “has been unable to get a part-time job because she's had to home school [their son] due to inadequate public school options.”

Perhaps the most distressing comment came from a family hit hard by an inadvertent misstep following what was to them new and complex rules: “Kicked off SSI because I have an IRA (didn't know this was not permissible) and am now reimbursing the govt. nearly \$10,000.” Situations such as this give rise to an impassioned plea to financial advisory professions to become more involved with education and outreach to families dealing with autism to forestall such unfortunate and costly misunderstanding of regulations, eligibility requirements, and financial opportunity and constraint under current tax law.

Implications for Financial Advisors

Increasing prevalence of autism touching persons in all walks of life means that there is an increased chance that a financial counselor or planner (hereafter financial advisors) will have a client who has a child, grandchild, niece, nephew, or other relative with autism. Financial advisors can play a vital role in guiding these clients through critical financial decisions.

In many respects, providing financial advice to a family that has a child with autism is not unlike providing financial advice to a family that has a child with any condition that limits the child's ability to be a financially independent, self-supporting individual. Provision for the child's future financial security must be made, regardless of the specific malady. If siblings are present, open discussions need to be held regarding distribution of family resources. In other important ways, however, (a) the spectral nature of autism, (b) the distinct characteristics of each child with autism, (c) the wide variety and differential cost of therapy, (d) the varying ability of parents to act as therapist for their child, (e) the differing levels of parental economic resources, and (f) the possible need to indirectly or directly interact with a wide

variety of medical and educational professionals makes planning the financial future for this group of children and their families unique.

It may be most useful to consider the process of advising families that have children with autism sequentially, beginning at first diagnosis and following through to end of life planning. When a family first hears the diagnosis of autism, listening is the best gift to give a client. Parents react to the diagnosis in a variety of ways (Nissenbaum, Tollefson, & Reese, 2002). Some cry, some are surprised, some are devastated and initially, most feel helpless. It takes time to process the information. Having an objective sounding board can help a client regain or maintain perspective at this juncture. Financial advisors also need to recognize that it is normal for parents of children with autism to grieve loss of the normally developing child they expected to have. Current grief theory indicates that episodes of grief may occur over the life cycle as different events such as birthdays, holidays, and relentless caregiving demands trigger a reaction (Worthington, 1994). Again, listening to a client talk about that grief in a non-judgmental, accepting manner can help a client deal with his or her emotions and face the hard task of making appropriate financial decisions in the current situation.

Following the initial shock of the diagnosis, parents typically want more information, but are not sure where to turn. Of course, financial advisors cannot and should not hold themselves out as experts on autism nor should they appear to unduly influence client decisions by the information given. Given that caveat, however, financial advisors could point clients to some respected sources of information on autism such as the Autism Society of America (www.autism-society.org), Centers for Disease Control (www.cdc.gov). If available, it is also helpful to point parents to local non-profit organizations that provide services for families that have children with autism, or to local, state or federal government agencies that disburse public dollars for autism treatment. This type of referral is no different from referring a client to a lawyer for estate planning or to a tax accountant to answer a complex tax question.

As a more objective voice outside the family circle, the financial advisor can help a client recognize and think through the financial aspects of caregiving and treatment options, anticipating some issues to facilitate being proactive versus reactive. Caregiving literature indicates that usually the mother adjusts employment hours to care for the child. Will one spouse reduce work hours or cease working to care for the child? If so, what impact will that decision have on family income now and in the future? What therapy options is the client considering? What is their cost? To what extent is public funding—federal, state, or local—available to cover treatment cost? Could the client or the client's spouse or other family provide some treatments or is the expertise of a specialist necessary? Where could the client be referred to learn about local program availability and participation rules? The advisor can encourage the client to weigh the evidence for or against a given therapy before proceeding with it. Clients need to be fully educated on the financial consequences of various ways of funding therapy, including the extremes of cashing in a 401k early, taking out a home equity loan, maxing out credit cards, or declaring bankruptcy. Impact of using family resources for the child with autism on financial resources available for siblings or other family financial needs should be considered as well.

A child who is high functioning may require therapy as a child, but having received that early intervention, be able to attend a regular school up to and including college, with or without support from trained professionals. In this case, a

client may want to consider ways to fund college savings for future use as well as identify ways to cover the costs of therapy today.

For a child who is mid-range to low functioning, financial plans must be quite different. Barton Stevens (ASA, 2004b), Chartered Lifetime Assistance Planner (ChLAP), founder and Executive Director of Life Planning Services in Phoenix, Arizona stresses the importance of attending to lifestyle, legal, financial, and government benefits issues when developing a long-range plan for care of a person with special needs.

Lifestyle includes decisions about such things as where a person will live, behavior management, education and employment activities, social activities and religious affiliation. Stevens encourages family caregivers to videotape typical caregiving routines, providing narration regarding steps and purpose if documentation of care directives are needed.

Legal issues focus on use of wills and trusts to distribute parental assets to benefit the disabled child. Power of attorney to act on behalf of the disabled person may need to be executed along with end of life health directives. Trusts for the disabled individual must be carefully arranged to provide professional money management, oversight of use, maintenance of government benefits, and protection of assets. Guardians, conservators, and trustees need to be named. Many families set up an *Irrevocable* Special Needs Trust to provide supplemental funds for exclusive use of the individual. Since assets in this form of trust are not in the name of the disabled individual, they will not risk loss of government health benefits.

Financial planning involves projecting current living expenses to the future for the expected lifespan of the disabled person to determine the size of the trust fund required to generate the needed income stream. Then, resources to fund the trust need be identified. Possible sources include stocks, life insurance, and other funds left at parent's death.

Government income and health care benefits (e.g. Supplemental Security Income and Medicaid) can be important resources for a disabled individual. Careful planning is needed to ensure the disabled individual receives what he/she is entitled to receive and assets that come to the disabled person from financial gifts, bequests, or other sources do not terminate benefits.

Stevens (ASA, 2004b) recommends that all plan documentation be placed in a single binder and family and caregivers notified of its location. Responsibilities of those involved in plan execution should be reviewed with each person. The entire plan should be reviewed on an annual basis and changes made as necessary.

Conclusion

Diagnosis of autism places a large financial burden on families who often must pay for expensive treatments out-of-pocket. Documented efficacy of early intervention heightens the intense pressure to use whatever means possible—including placing the family's financial future at risk—to secure needed therapy NOW. Limited public and private support exists to help families in that endeavor. As noted by many respondents in this study, programs offered through public education are often inadequate or inappropriate for a given child. While parents can at times substitute their labor for that of a trained service provider, doing so usually precludes securing paid employment resulting in lower family income that must meet rising expenses.

There is great need for professionals within the financial counseling and planning community to reach out to families struggling to help a child with autism. Consider charging reduced fees or doing pro bono work for low and middle-income families who could not otherwise obtain financial help in meeting the needs autism creates. Guide them through difficult but necessary financial decisions. Help them sort out options and financial consequences of decisions. Assist them in making financial plans for the future even in the face of immediate and urgent financial needs. Connect them with reliable sources of information about autism. Given the dramatic increase in autism in recent years, the need for advisors skilled in helping families with the financial aspects of having a child with autism can only grow.

References

- Aneshensel, C. S., Perline, L. L., & Schuler, R. H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior*, *34*, 54–70.
- Amo, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs*, *18*(2), 182–188.
- Autism Society of America [ASA]. (2004a). *IDEA and your child's rights*. Retrieved May 25, 2005 from <http://www.autism-society.org/site/PageServer?pagename=IDEA>
- Autism Society of America [ASA]. (2004b). *Planning for the future*. Retrieved May 25, 2005 from <http://www.autism-society.org/site/PageServer?pagename=livingplanning>
- Autism Society of America [ASA]. (2004c). *Treatment and education*. Retrieved May 25, 2005 from <http://www.autism-society.org/site/PageServer?pagename=TreatmentEducationOverview>
- Autism Today. (n.d). *One in four Americans know someone with autism*. Retrieved May 29 2005 from http://www.autismtoday.com/articles/One_In_Four_Americans_Know_Someone_With_Autism.htm
- Autism Victoria. (2005). *Diagnosis and definitions*. Retrieved May 25, 2005 from <http://www.autismvictoria.org.au/diagnosis/>
- Betts, D. (2005). *Art therapy and autism*. Retrieved May 25, 2005 from <http://www.art-therapy.us/autism.htm>
- Beutler, I., & Owen, A. (1980). A home production activity model. *Home Economic Research Journal*, *9*(1), 16–26.
- Bryson, S. E., Rogers, S. J., Fombonne, E. (2003). Autism spectrum differences: Early detection, intervention, education, and psychopharmacological management. *Canadian Journal of Psychiatry*, *48*, 506–516.
- Centers for Disease Control and Prevention. (2005). *How common is autism spectrum disorder (ASDs)?* Retrieved May 23, 2005 from http://www.cdc.gov/ncbddd/autism/asd_common.htm.
- Deacon, R. E., & Firebaugh, F. M. (1988). *Family resource management: Principles and applications*. Boston: Allyn and Bacon.
- Fewell, R. R. (1993). Child care for children with special needs. *Pediatrics*, *91*(1), 193–198.
- Fombonne, E. (2001). Is there an epidemic of autism? *Pediatrics*, *107*(2), 411–412.
- Fombonne, E. (2003a) Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, *33*(4), 365–382.
- Fombonne, E. (2003b). Modern views of autism. *The Canadian Journal of Psychiatry*, *48*(8), 503–505.
- Fulton, P., Samonte, S., Tierney, J., Conno, J., & Powell, L. (2001). Effective sampling of rare populations elements: Black female caregivers and noncaregivers. *Research on Aging*, *23*(60), 694–712.
- Gould, E. (2004). Decomposing the effects of children's health on mother's labor supply: Is it time or money? *Health Economics*, *13*(6), 525–541.
- Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation*, *102*, 319–345.
- Järbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *33*(4), 395–402.

- Kahana, E., Biegel, D. E., & Wykle, M. L. (1994). *Family caregiving across the lifespan*. Thousand Oaks, CA: Sage.
- Kanner, L. (1943). Autistic disturbances of affective contact. *The Nervous Child*, 2, 217–250.
- Larsson, E. V. (2005). *Intensive early intervention using behavior therapy is no longer experimental*. Lovaa Institute for Early Intervention. Retrieved May 25, 2005 from <http://rsaffran.tripod.com/ieibt.html>
- Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The consequences of caring: Effects of mothering child with special needs. *Journal of Family Issues*, 25(3), 379–403.
- Marcus, L.M., Rubin, J. S., & Rubin, M. A., (2000). Cost-benefit analysis and autism services: A response to Jacobson and Mulick. *Journal of Autism and Developmental Disorders*, 30(6), 595–598.
- Marks, N. F. (1996). Caregiving across the lifespan: National prevalence and predictors. *Family Relations*, 45, 27–36.
- Marks, N. F. (1998). Does it hurt to care? Caregiving, work-family conflict, and midlife well-being. *Journal of Marriage and the Family*, 60, 951–966.
- Mesibov, G. B. (2005). *What is TEACCH?* Available online at: <http://www.teacch.com/aboutus.htm> (accessed on April 12, 2006).
- Meyers, M. K., Lukemeyer, A., & Smeeding, T. (1998). The cost of caring: Childhood disability and poor families. *Social Service Review*, 72, 209–233.
- Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002) The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities*, 17(1), 30–43.
- Payndya, S. (2005). *Caregiving in the United States: Research report*. Retrieved May 25, 2005 from http://www.aarp.org/research/housing-mobility/caregiving/fs111_caregiving.html
- Schall, C. (2000). Family perspectives on raising a child with autism. *Journal of Child and Family Studies*, 9(4), 409–423.
- Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving transitions during a three-year prospective study. *The Gerontologist*, 40, 165–178.
- Sheinin, A. G. (2006). The high cost of autism. *The State*. Retrieved June 21, 2006 from http://web.lexis-nexis.com/universe/document?_m=e66a4a06e11b93a7a65aaef647d677bb&wchp=dGLbVzb-zSkVA&_md5=83a3902e95cbc4b1629cfdd1735e5bb9
- Silverstein, R. (2005). *A user's guide to the 2004 IDEA Reauthorization*. Washington, DC: Center for the Study and Advancement of Disability Policy. Retrieved June 21, 2006 from <http://www.c-c-d.org/IdeaUserGuide.pdf>
- Straus, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage.
- Tseng, S. (2005). *Severe medical conditions and the loss of health insurance coverage: Evidence from the Health and Retirement Study*. Retrieved May 5, 2006 from: <http://home.uchicago.edu/~htseng/hrstse.pdf>
- Tarkan, L. (2002). Autism therapy is called effective, but rare. *New York Times*. Retrieved May 25, 2005 from <http://www.spedalliance.com/autism.htm>
- University of Michigan Health Systems [UMHS]. (2005). *Autism and pervasive developmental disorders*. Retrieved May 25, 2005 from <http://www.med.umich.edu/1libr/yourchild/autism.htm>
- Worthington, R. C. (1994). Models of linear and cyclical grief: Different approaches to different experiences. *Clinical Pediatrics*, 33(5), 297–300.