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## The Financial Side of Autism: Private and Public Costs

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### 1. Introduction

First identified by Leo Kanner in the early 1940s, autism is a biologically based developmental disorder that impairs an individual's ability to communicate, build relationships, and relate appropriately to the environment (Kanner, 1943). Diagnosis is usually made in early childhood after a multi-disciplinary assessment of behavior, developmental level, and communication ability. Boys are four times as likely as girls to be affected (Fombonne, 2003a, 2005).

Initially, autism was considered a rare disorder. An early epidemiological study conducted in England in the 1960s documented a 0.05% prevalence rate (4.5 per 10,000) (Lotter, 1966). Prior to the 1980s, recorded incidence of autism disorder in the United States was also low, affecting about 1 in every 2,000 children (Fombonne, 2009; Rutter, 2005). In the 1990s, the American Psychiatric Association broadened diagnostic criteria and included Asperger's syndrome and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) with Autism Disorder under Autism Spectral Disorder (ASD) (Centers for Disease Control, 2009). In this article, the terms autism and ASD are used interchangeably.

Autism is now known to affect children world-wide, regardless of race, ethnicity, or socio-economic status (Naqvi, 2009). Documented prevalence rates vary. In the United States, the current ASD prevalence rate is 1 in every 110 births (1 in 70 boys) (Centers for Disease Control, 2009), representing an average increase of 57% over 2002, 600% over the last two decades (Dawson, 2010; Wang & Leslie, 2010). Prevalence rates in Western Europe, Canada, and Australia are similar to those in the United States (Grossman & Barrozo, 2007; Naqvi, 2009), whereas rates in Japan and China are somewhat higher (Naqvi, 2009; Wong & Hui, 2008). Prevalence rates in Western Europe and Canada are similar to those the United States. In recent years, the number of cases in Latin America, Asia, the Middle East, and Africa has increased as well (Grossman & Barrozo, 2007).

No consensus regarding cause exists (Fombonne, 2003b). Reasons for the surge in incidence of autism are ardently debated. Autism has no known genetic or biological markers. Diagnosis relies on observation of behavior and professionals may differ in application of diagnostic criteria. Some have argued that the recent surge in numbers simply reflects increased awareness of symptoms and better diagnostic tools (Cohen & Spenciner, 1996;

Gernsbacher, et al., 2005). Others counter that while improved understanding of autism may account for some of the increase; it fails as a satisfactory explanation of all of the growth in diagnosed cases (Yazbak, 2003).

Autism can be an expensive disorder. Diagnosis and therapeutic intervention can be a lengthy and labor intensive process. Families can spend more than \$50,000 per year on autism-related therapies such as applied behavioral analysis (ABA) (National Conference of State Legislatures [NCSL], 2010). Treatment may involve use of costly foods or dietary supplements. Prescription of psychotropic medications can lead to frequent use of the medical system. Health care costs for individuals with ASD can be as much as 45% higher than otherwise comparable individuals without ASD (Croen, et al., 2006). Further, individuals with ASD are likely to have other types of disabling medical conditions, increasing use of inpatient and outpatient care services (Mandell, et al., 2006).

ASD-related costs are not limited to the cost of therapeutic or medical intervention. As with 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 things such as specialized childcare and educational materials. Caregiving demands can force parents to reduce work hours or leave the labor market (Gould, 2004)

ASD is now considered a significant and growing public health concern due to the rapid increase in prevalence and high cost of therapeutic interventions and care (Newschaffer & Curran, 2003; Grossman and Barrozo, 2007). Greater understanding of the costs associated with ASD is needed to guide service planning, allocation of private and public sector resources to those affected by autism, and evaluation of market systems and public policies that affect access to and cost of autism-related services.

This article reviews what is currently known about the type, amount, and distribution of autism-related financial costs relative to family and society. Estimates of the broad social costs of autism are compared. Components of the financial burden on family members are examined. Current avenues to sharing some of this financial burden with the public and private sector are reviewed. The article concludes with recommendations for future research.

## **2. Total cost of autism: Estimates and issues**

Autism is complex. Considerable heterogeneity exists among those affected by it. A wide spectrum of health care, education, and social service agencies provide diagnostic services, therapeutic interventions, and medical care related to autism, each with their own recordkeeping standards and data considered relevant. Sharing of information or data across agencies is limited. In addition, most of the costs borne by families of children with autism occur outside the market and are difficult to quantify. These facts make it challenging to obtain a comprehensive measure of autism-related expenditures. To date, no single representative data base captures all of the costs and expenditures related to autism spectrum disorders. Consequently, to inform public policy decisions, researchers have used available data and estimates in efforts to quantify ASD-related expenditures.

Given the challenges in data collection, the prominent role of medical care in the lives of children with ASD, and the availability of medical data, much attention has been given to measurement or estimation of medical costs and expenditures. Researchers have assessed use and cost of health care for children with ASD (e.g. Croen et al, 2006; Liptak, et al., 2006), and have developed broader measures that account for the indirect as well as the direct costs

associated with ASD (e.g. Ganz, 2006, 2007). Researchers have used survey data (e.g. Järbrink & Knapp, 2001), institutional or government health care usage and cost data (e.g. Shimabukuro et al., 2008; Wang & Leslie, 2010) or constructed synthetic expenditure estimates using published cost and use data and prevalence rates (e.g. Ganz, 2006, 2007). Incidence of autism is worldwide. Research on the costs associated with ASD has been conducted in the United States (e.g. Croen, et al. 2006), the United Kingdom (Järbrink & Knapp, 2001), Sweden (Järbrink, 2007), and, recently, China (Xiong et al. 2011) and Egypt (Mendoza, 2010). More remains to be learned about autism-related costs in developing countries, however.

Key findings of recent studies of autism-related costs conducted in the United States and abroad are summarized in Table 1. To facilitate comparison, all monetary values in the table have been converted to 2011 United States dollars. A brief review of each study follows.

Croen, et al. (2006) used data from the Kaiser Permanente Medical Program in Northern California, a large group health care plan, to compare health care utilization and expenditures of children aged 2 to 18 with and without ASD. On every measure considered the health care cost for children with ASD was higher. Children with ASD had higher average total clinic, pediatric and psychiatric outpatient visits. A larger percent of children with ASD had inpatient and outpatient hospitalizations (3% vs. 1% for inpatient and 5% vs. 2% for outpatient). Children with ASD were about twice as likely to use gastrointestinal medications and 9 times more likely to use psychotherapeutic medications. Average cost for children with ASD were twice as high as other children for hospitalization, clinic visits, and prescription medications. Age and gender adjusted total cost per member was on average almost 3 times higher for children with ASD. Among children that had psychiatric conditions, total average annual costs were 45% higher for children who also had ASD.

Liptak, et al. (2006) also examined the health care use and expenditures of children with ASD. Instead of using data from one specific health care provider however, researchers examined cross sectional data from 3 national surveys: the Medical Expenditure Panel Survey, the National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Care Survey. Similar to Croen, et al. (2006), Liptak et al. (2006) found that, as compared with other children, children with ASD had more outpatient visits, physician visits, and prescription medication. Also, physician visits for children with ASD lasted an average of about 15 minutes longer than those of children without ASD. Annual medical expenses for children with ASD were over 7 times higher.

Mandell, et al. (2006) used Medicaid data from Allegheny County, Pennsylvania from 1994 to 1999 to compare medical expenses of minor aged children with and without an autism diagnosis. Total expenditures equaled the sum of reimbursed charges per person per year for ambulatory care, emergency care, hospitalization, psychiatric hospitalization and psychiatric outpatient care. Average expenditures were calculated using data on only those with that expense. Average annual Medicaid spending for children with ASD was 3.5 times that of children with mental retardation and nine times that of other children, largely due to dissimilar inpatient and outpatient psychiatric expenditures.

Leslie and Martin (2007) conducted a comprehensive assessment of health care spending on children with ASD age 17 and under using a large, national database containing claims information from the private health plans of large employers. This estimate was compared with that of children that had a mental disorder using inflation-adjusted annual figures 2000 through 2004. Health care spending equaled the sum of actual amounts paid by the patient (e.g. deductible or co-pay), the patient's insurance plan and any other insurance for inpatient, outpatient, and pharmaceuticals.

Authorship	Data Source	Sample	Expenditures
			Developed Country per person per year estimates
Croen et al. 2006	Kaiser Permanente Northern CA 2003-2004	3,053 children with autism diagnosis	Total Medical: \$3,190 Inpatient: \$1,650 Meds: \$847 Other: \$660
Liptak et al. 2006	National sample from MEPS 1997- 2000	31 children with autism diagnosis	Total Medical \$8,140 Inpatient: \$968 Meds: \$1,287 Other: \$5,830
Mandell et al. 2006	Allegheny County, PA Medicaid data 1994-1999	334 children with autism diagnosis	Total Medical \$13,200 Inpatient: \$9,130 Other: \$4,070
Leslie and Martin 2007	Large US self- insured employers	256,646 children with mental disorder diagnosis 2000-2005	Total Medical \$6,995
Wang and Leslie 2010	Medicaid data for 42 states; fee-for-service	2,184,677 children with mental disorder diagnosis; 49,921 with autism, 19,621 with other ASD	Autism: \$27,400 Other ASD: \$24,410  Total health care cost per 10,000 for children with ASD \$2,024,326
			Developed Country: lifetime estimates
Järbrink and Knapp 2001	Center of Economics data & survey of 250 parents	228 children with autism or high functioning autism	Autism \$2,293,250 High Functioning Autism \$859,000
Ganz 2006	Synthetic estimate		\$3,783,780
Knapp, et al., 2007	Synthetic estimate		Low Functioning: \$8.1 million High Functioning: \$4.9 million
Xiong, et al., 2011	Clients in 3 Beijing rehab. institutions	227 children; 61 with ASD	\$2,984
Mendoza 2010	Probability sample Greater Cairo Region	174 persons with ASD	Direct financial costs for surveyed households ranged between \$37,560- \$55,080

Table 1. Summary of cost and expenditure studies for individuals with ASD; all monetary amounts converted to 2011 US\$. Table adapted from Boudier, et al. (2009).



Treated prevalence of ASD was low relative to other mental disorders reported in the database. But, over the 5 years of the study, ASD prevalence increased 101.1%, which was a substantially higher rate than all other mental disorders except bipolar disorder at 106%.

Expenditure among ASD patients was relatively high, however. Between 2000 and 2004, mean ASD expenditures increased 26.1% per patient. Computing total health care expenditures per 10,000 covered lives, the researchers found expenditures for ASD patients increased markedly over the 5 years, from \$47,378 per 10,000 (2000\$) to \$114,710 per 10,000 (2004\$), a 142.1% increase. They note, however, that in the context of the data utilized in the study, ASD related expenditures were smaller than those associated with more common mental health conditions. As a comparison, hyperactivity had the highest cost burden with an average of \$406,238 during the same time frame.

Wang and Leslie (2010) examined trends in health care expenditures associated with ASD using Medicaid from 42 states. Their focus was children aged 17 or younger who were continuously enrolled from 2000 to 2003 in fee-for-service Medicaid with a mental disorder diagnosis. Treated prevalence of ASDs in the data increased almost 29% over the four years observed, the largest increase among the mental disorder diagnostic groups. Average total health care expenditures per treated child were \$27,400 (2011 US\$) for autism; \$24,410 (2011 US\$) for any other ASD. Total health care expenditures for ASDs per 10,000 covered lives increased 32.8% between 2000 and 2003.

A few studies have attempted to estimate lifetime costs. Järbrink and Knapp (2001) used autism prevalence rates and cost data from several prior national research studies and reports to estimate costs associated with service use, lost productivity of those with autism, and family time cost and expenses in Britain. They considered two scenarios. The average lifetime cost for someone with autism and an additional learning disability was £2.94 million (\$4.77 million 2011 US\$). For someone with high functioning autism, lifetime cost was estimated to be £785,000 (\$1,274,840 2011 US\$). For both groups, living support was the highest expense at 87% of total cost for those with autism and an additional learning disability and 40% of total cost for those with high functioning autism. They note that their estimates were highly sensitive to prevalence rates. Drawing on then current research, they used a prevalence rate of 5 per 10,000 (Fombonne, 1998).

Rather than survey parents regarding the specific costs that they bear, Ganz (2006, 2007) relied on published cost and usage data from various sources to estimate total costs associated with having a child with autism. Ganz classified costs as direct and indirect. Direct costs included the value of goods and services consumed as well as medical and nonmedical costs. Indirect cost focused on value of employment-related productivity lost by individuals with autism and their families as a result of autism-related time demands. Since these costs were not observed in the market, an opportunity cost approach was used to estimate their value. This approach is based in economic theory of opportunity cost. It identifies the value of other services that could have been obtained had resources not been consumed by or for individuals with autism.

Knapp, Romeo, and Beecham (2007) calculated aggregated cost of ASD for the United Kingdom. Data on prevalence, level of functioning, place of residence, and cost per individual were drawn from national surveys, published research, own prior studies and expert opinion. Individual level costs were multiplied by estimated prevalence rates, stratified by age (0 – 3, 4-11, 12-17, adult), level of functioning (high or low), and residence (foster/residential care or private family household).

Average annual costs per child ranged between £16,185 and £62,536 (\$26,220 and \$101,308, 2011 US\$) for children with low functioning ASD, depending on age and residential placement. For children with high functioning ASD, the range was £1,214 to £21,090 (\$1,967 to \$13,076 2011 US\$). It was assumed all high functioning children would reside at home with family. Average annual cost per adult ranged between £14,124 and £75,840 (\$22,880 and \$122,861 2011 US\$) for low functioning adults and between £13,076 and £67,514 (\$21,183 and \$109,373 2011 US\$) for high functioning adults. These adult estimates do not include value of lost employment for the person with ASD at either level of functioning or the value of welfare benefits for low functioning adults. Considering lost employment would add, on average, an amount equivalent to \$34,154 to average annual cost per adult. Considering welfare benefits would add approximately \$1,500 to \$10,860 (US\$), depending on residential status.

Aggregate annual national cost for all children with ASD was £2.7 billion (\$4.3 billion 2011 US\$) with about 63% of that cost attributed to children with low functioning ASD. Aggregate annual national cost for all adults with ASD was £25 billion (\$40.5 2011 US\$), with about 66% of that cost attributed to adults with low functioning ASD. Knapp et al. (2007) estimated lifetime costs for someone with low functioning ASD at £4.7 million (\$7.6 2011 US\$) and at £2.9 million (\$4.6 2011 US\$) for high functioning ASD.

Incidence of autism is world-wide. Two recent studies examined costs associated with ASD in developing countries. As in the United States, prevalence rates of ASD in China have grown dramatically. Prior to 1980, average prevalence of ASD in China was close to 2 per 10,000, whereas after 1980 it has been 14.8 per 10,000. Median prevalence of ASD among children aged 2 to 6 from 2000 on is 10.3 per 10,000 (Sun & Allison, 2010).

Xiong et al. (2011) used data from 227 parent interviews to calculate difference in family income, living expenses, and economic assistance between families with and without a child with autism. Living expenses included spending on education, health care, as well as such things as clothing, "caring cost," and "amusement cost." Result of this calculation was deemed to be the annual financial burden of raising a child with autism. Researchers found cost was highest for families with a child with autism, followed by families with a child with a physical disability and mental disability. Bivariate regression analysis indicated that autism was a significant predictor of family spending on education, medical, caring, and clothing, but not for amusement or educational toys.

Mendoza (2010) conducted the first known study of autism-related costs in Egypt using survey data gathered from a probability sample of 165 households in the Greater Cairo Region. In contrast to the United States and European countries, Mendoza found few families used ASD interventions or institutionalized autism-related services, citing lack of knowledge about ASD and effective interventions, limited state or community resources, limited financial resources, and pessimism regarding the family member with autism as reasons why. Most individuals with ASD (91.2%) relied on immediate family for care; family members expected to continue to provide that care for the lifetime of the disabled member. The widespread use of home based care resulted in direct financial cost estimates that were considerably lower than similar estimates obtained in developed countries. The majority of costs were for non-medical items such as special education, skills training, or camps rather than for medical services, prescription medication, or behavioral therapy.

Examining results across these expenditure studies, several conclusions may be drawn. Provision of services to those with ASD requires a large investment of family and social resources. Consequently, meeting the needs of those with ASD generates significant opportunity costs for all sectors of society. Care costs for those with ASD are several times higher than that of other individuals, both with and without disability. For those with ASD, medical costs in general and pharmacology costs in particular appear to be a large share of expenditures. Both annual and lifetime cost estimates can vary greatly, depending on such things as the age of the individual, residential situation (family vs. institutional), and degree of function. Costs associated with ASD in developed countries with established social service, education, and medical sectors are considerably higher than costs in developing countries that lack such services. Worldwide, families bear a significant portion of the financial burden of ASD. In developing countries, virtually all of the care costs fall to family. The portions of the caregiving burden that family cannot sustain will inevitably spillover to society in one form or another.

An obvious and major weakness of all cost estimates is that they are highly sensitive to the assumptions made regarding any component part. Counts and costs are documented for such things as physician visits, but value of non-market costs such as reduction in parent employment is difficult to capture and monetize. Government and community resources can differ greatly by state, let alone by country, reducing ability to make meaningful comparisons. In absence of any other methods, the estimates are useful. But, clearly, a superior method would be development and use of comprehensive, longitudinal data collections on the characteristics and expenditures of those with ASD across the lifespan.

### 3. Family cost burden

Autism spectrum disorder places an enormous burden on families. Some costs such as out-of-pocket expenditures for diagnosis and treatment can be quantified. Other costs such as the value of lost leisure and employment time, and lost income can be estimated. Still other costs such as increased stress, disruption of family life, or reduced time with other family members can only be recognized. Relatively few studies have attempted to measure the cost of the informal care provided by family members. Each of these studies has used a different methodology and examined the question from a somewhat different perspective.

Endeavoring to improve methods for gathering data on family informal care, Järbrink, et al. (2003) conducted a pilot study with 15 families in the United Kingdom that had one or more children with autism between ages 4 and 10. Families were asked to keep a diary of autism-related time and money expenditures for 14 days. Questionnaires were also administered. The authors used parent records and questionnaire responses to determine the average cost of informal care, select out-of-pocket expenses, service use, and income losses. They also compared the type and amount of data gathered by each method and evaluated the strength and weakness of each approach.

Children in the study varied in severity of the disorder and presence of other disorders. Of the seventeen children in the study, eleven had an autism diagnosis, three were diagnosed with atypical autism, two had Asperger syndrome and one had semantic pragmatic disorder. Several of the children had some type of co-morbidity. Seven children had some degree of mental retardation. Two had chronic bowel syndrome, one had epilepsy and another had gluten intolerance.



Parents reported spending nearly 60 hours per week caring for their child due to autism spectral disorder. They estimated that if their child was not on the autism spectrum, they would have spent an average of 40 hours per week in other activities with about half of those hours (22 hours) allocated to paid work. Interestingly, several reported that if there were no need to care for their child, their amount of unpaid work would actually decrease because paid work would replace current volunteer activities. Parents estimated they lost 11 hours of leisure per week due to care for their child.

Järbrink et al. (2003) found that average total out-of-pocket expenditures per child for goods and services other than education, early intervention therapy, health services and medications were about 52% higher in the diary survey than the questionnaire. They concluded use of long recall periods in expenditure studies would likely underestimate out-of-pocket spending noting that smaller outlays were apparently forgotten when completing the six month retrospective in the questionnaire.

Service use expenses were divided among education (mean weekly cost £223.82 or \$363.48 2011 US\$), early intervention therapy (mean weekly cost £144.38 or \$234.47 2011 US\$) and health and social services (£20.12 or \$32.67 2011 US\$). All of the children were either in a special school setting (e.g. boarding school or private school) or had special support in a mainstream school. Ten of the children received early intervention therapy where parents paid about a third of the cost. Health and social service cost focused on in-patient hospital care, social services respite care and clinical psychologist appointments.

Although all parents reported that their child's condition had a negative effect on career or income, only eleven could give a numerical estimate of that loss. Average weekly loss reported by parents was £231 (\$375 2011 US\$) with a median of £250 (\$406 2011 US\$). Most estimates were in the range of £200 to £450 (\$325 to \$731 2011 US\$) per week.

Combining cost estimates for education, early intervention therapy, health and social services, voluntary support, medication, other costs paid by parent (e.g. for damages, certain food or clothing, toys), and income losses, Järbrink, et al. (2003) determined that the total societal cost for a child with autism in the study was £689 (\$1,119 2011 US\$) if the only time cost considered was reported income lost. However, if a human capital approach were used to place a value on time spent in informal care, weekly cost would increase to £855 (\$1,388 2011 US\$)

Using data gathered in the Family Experiences with Autism survey, Sharpe and Baker (2007) assessed responses from 333 parents of minor age children with autism to investigate factors associated with experiencing financial problems. Parents were asked about use various types of interventions including Applied Behavioral Analysis, speech and language, sensory integration, diet modification, special education, music therapy, riding therapy, and medical intervention. Parents also reported on unreimbursed out-of-pocket expenses for medical doctor or therapy, prescription and nonprescription drugs, and education expenses. Two unique contributions of their study were use of multivariate analysis to identify significant contributors to experiencing financial problems while holding demographics and economic resources constant and use of qualitative methods to identify themes in parent report of experiences.

Comparing the characteristics of those who did and who did not report having financial problems in the past 12 months due to autism, the researchers found that, among those reporting financial 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 in this group had used speech and language therapy or special education. No significant difference was found between the two groups for child age, use of Applied Behavioral Analysis (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.

Two results stood out in the multivariate analysis of factors affecting likelihood of financial problems. 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%, and 289%, respectively). Second, consistent with previous research and as would be expected, those with annual income under \$40,000 were more likely to have financial problems than those with annual incomes of \$60,000 or more. These results suggest that, while all families with a child with autism may struggle to meet the demands of the disorder, for low income families the demands can quickly outstrip family resources. For that reason, special attention needs to be given to low income families in the design and delivery of programs and public policy.

The researchers also used qualitative research methods to identify common themes in parent report of reasons for financial difficulty. Most were caught between rising expenses and reduced income. One of most salient sources of financial pressures according to the parents was the high cost of therapy, especially Applied Behavioral Analysis, as well as special foods or supplements. Medical expenses of other family members could increase as well. As one parent reported, "other family members need[ed] counseling and medication to cope with the stress of living with an autistic child." (Sharpe & Baker, 2007, p. 259)

Another common source of financial struggle was lost income due to reducing work time to manage care of the child. This situation exacted an emotion cost as well. Many of the parents expressed anguish or anger at having to leave the labor market or desperation and fear when considering how to meet financial demands with the income loss. An important insight given by the parents was that care management extended well beyond meeting the child's physical needs. Parents reported struggles with insurance providers to obtain or continue coverage for health related services; protracted battles with school administrators to obtain specific education services or starting to home school their children in an attempt to meet their educational needs. Scheduling and transportation to various therapies and medical appointments also took a toll on parent time. Other sources of financial pressure included replacing items broken, damaged, or destroyed by the child and retraction of public program support due to a misunderstanding of program rules.

A poignant aspect of parent report was the extent to which parents mortgaged their own future to obtain therapy and services for their children with autism. Parents cashed out their retirement investments, sold stock, drained the equity in their home, and borrowed money to the point that bankruptcy seemed inevitable. One desperate family reported "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" (Sharpe & Baker, 2007, p. 259).

### 3.1 Family financial planning issues

Planning the financial future of a family with a child on the autism spectrum is a complex process. There are many important considerations not shared by families with

neurotypical children. Family ability to engage in financial planning varies greatly. As noted, funding autism treatment can devastate the financial resources of some families and leave little hope for rebuilding the spent wealth. Seeking ways to help a child with autism, families have taken out a home equity loan, charged credit cards to the limit, or declared bankruptcy after exhausting their financial resources. Although a parent's desire to secure help at any cost is understandable, these actions have long term financial consequences for family and potentially society as well. In absence of reform of methods to fund autism treatment, families in this situation will continue to struggle to maintain income and may have to seek help from relatives and public assistance programs just to cover basic expenses.

The unique characteristics of children with ASD leads to wide variation in future care needs. High functioning children may require expensive intense therapy while young, but then incur minimal to no additional autism-related expenses in adolescence or adulthood. Children in this group may be able to support themselves as adults. In this situation, family financial plans could focus on funding post-secondary education and training.

Financial plans for a child that is mid-range to low functioning are quite different. Parents must arrange for care to continue after their death. Attention must be paid to lifestyle, legal, financial, and government benefit issues. Decisions must be made regarding where the disabled person will live, behavior management, education and employment activities, as well as social and religious activities.

Wills and trusts can be used to distribute parental assets to benefit the disabled child. Careful planning is needed to ensure the disabled individual receives what he/she is entitled to receive and assets transferred from financial gifts, bequests, or other sources do not jeopardize other potentially important sources of income or health care support such as Supplemental Security Income or Medicaid. Arrangements need to be made to provide professional money management, oversight of use, maintenance of government or other benefits, and protection of assets. Guardians, conservators, and trustees need to be named. Power of attorney to act on behalf of the disabled person may need to be executed along with end of life health directives. Plans should be reviewed annually and changes made as necessary.

#### **4. Cost sharing: Public and private sector**

Central to public policy discussion of autism is deliberation regarding who should share the cost of treatments, to what extent, and by what mechanisms. Much attention has been focused on access to and funding for applied behavioral analysis (ABA). ABA uses discrete trial training help individuals with ASD learn life, social and communication skills. ABA is an early intervention therapy that appears to be most effective when applied in the preschool years. Since it is delivered one-on-one with a trained therapist, it is very expensive. But, because its efficacy has been supported in the scientific literature, it is highly sought after by families with a child with autism as a therapeutic intervention.

Families in the United States have sought respite from the high costs of ASD in the federal Individuals with Disabilities Education Act (IDEA), state Medicaid waivers, and state health insurance mandates. Although each of these items offer some help for families with a child with autism, program structure and funding limits often curtail the type and amount of help actually received from these programs.

#### 4.1 IDEA

The Individuals with Disabilities Education Act (IDEA) is a federal law passed in 1990 that addresses education needs of children with disabilities from birth to either age 18 or 21, depending on the disability. The intent of IDEA was to guarantee a free and appropriate education for every child with a disability, including ASD. Under IDEA, schools have typically offered speech and language therapy. Although speech and language therapy is important for most children with ASD, recently, attention has focused on provision of Early Intensive Behavioral Intervention (EIBI), usually in the form of Applied Behavioral Analysis (ABA). Given the high expense of ABA, parents have requested that school districts provide, fund, or reimburse them for ABA therapy for their child under the “free and appropriate” provision of IDEA. When refused, some parents have taken schools to court. Generally, when schools have correctly processed a student’s Individual Education Plan, have hired qualified staff, used research-supported practices in educational programs, and collected meaningful data to monitor student progress and program effectiveness, courts have ruled in the schools favor (Yell & Drasgow, 2000).

As a practical matter, however, in times of cutbacks in education funding, school districts cannot afford the high cost of ABA therapy for each child with an autism diagnosis. Even if they could, they could not hire 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. Consequently, in practice, “appropriate education” does not mean ideal, nor is it necessarily what parents believe is best for their child (Tarkan, 2002).

#### 4.2 Medicaid waivers

Medicaid is a means-tested program designed to help persons that have low income and resources access health care. The program is funded by the federal and state governments. Although Congress and the federal Centers for Medicare and Medicaid Services have established the general rules for program operation, each state administers its own Medicaid program. Consequently, eligibility criteria can differ somewhat from state to state.

Medicaid waivers allow states to provide home and community based services to individuals that do not meet all eligibility criteria but, without the services provided by the waiver, would require long term institutional care. Total cost to Medicaid to provide services under the waiver cannot exceed what Medicaid would have paid for service in an appropriate institutional setting.

In 2007, Colorado, Indiana, Maryland and Wisconsin were the only states with Medicaid waivers focused specifically on children with autism. Since that time, Indiana, Kansas, Maryland, Massachusetts, Missouri, Montana, Nebraska, North Dakota, and Pennsylvania have received Medicaid waivers for autism. Most of these autism waivers focus on provision of service to children, although Pennsylvania has a waiver specifically for adult autism (Centers for Medicare and Medicaid Services [CMS], 2011). In a majority of the remaining states, autism is included in the state’s definition of developmental disability and covered under a Medicaid developmental disability waiver. A few states, however, explicitly exclude autism from the state developmental disability definition unless the person also has mental retardation (Spigel, 2007).

Unfortunately, in practice, relatively few individuals with autism can obtain services under a waiver. Since persons must otherwise require long-term institutional care to be eligible, those at the high functioning end of the autism spectrum could not qualify. To



control costs, states can cap waiver enrollment leading to long waiting lists. In states that focus on providing early intervention behavior therapy under the waiver, children on a long waiting list might no longer be eligible for services once an opening occurred (Spigel, 2007).

Future Medicaid funding is another concern. Medicaid represents about one-fifth of total state spending (National Association of State Budget Officers, 2010), making it one of the largest components of state budgets. The severe national recession in the late 2000s squeezed states between substantial declines in revenue and increased demand for public services, including Medicaid. According to the National Association of State Budget Officers, fiscal years 2009 and 2010 were two of the most difficult years for state budgets since the Great Depression. Attempting to meet budget shortfalls, 41 states made mid-year budget cuts during fiscal 2009; 39 states did so in 2010 (National Association of State Budget Officers, 2010). Across all states, Medicaid and education (K-12 and higher education) bore the brunt of these budget cuts. Given a slow economic recovery, tight state budgets are expected to continue into 2012 and beyond, thus restricting resources available to fund services for families that have a child with autism.

#### **4.3 State health insurance mandates**

The health insurance industry has generally excluded or strictly limited coverage for autism-related diagnosis and treatment, arguing that therapies such as ABA are an education intervention that should be funded by the public schools instead of health insurance. In recent years, diligent lobbying efforts from autism advocacy groups and families with a child with autism have resulted in passage of insurance mandates for autism in many states. In fact, a majority of the laws providing coverage for autism has been passed in the last three years (National Conference of State Legislatures [NCSL], 2010).

A health insurance mandate is a requirement that state law places on health plans or insurance providers in that state. Mandates typically force health plans or insurance providers to extend coverage to a broader population than they otherwise would. Some states only require that certain types of coverage be offered. Individuals and employers can accept or reject the coverage, giving the purchaser some control over policy content and cost. Other states disallow choice and require the mandate to be a part of all policies sold in the state (American Speech-Language Hearing Associates [ASHA] 2011)

Living in a state with an autism health insurance mandate does not guarantee adequate coverage of autism-related treatment or medication, however. Individuals along with small and medium sized employers purchase health insurance in the market. Large employers have the resources to self-insure. Self-insured plans are governed by the Federal Employee Retirement Income Security Act (ERISA) and are exempt from state law. Currently, 55 % of enrollees in a private sector plan are in a self-insured plan (Fernandez, 2010).

As of March 2011, all states except Alaska, Delaware, South Dakota, and Wyoming had passed a state insurance mandate related to autism diagnosis and treatment. Eighteen states have a mental health parity law that may include autism spectrum disorder as a covered mental illness: Alabama, Arkansas, California, District of Columbia, Georgia, Hawaii, Michigan, Minnesota, Mississippi, Nebraska, North Carolina, North Dakota, Ohio, Rhode Island, Utah, Virginia, Washington and West Virginia. Mental health parity laws mean that financial payments (e.g. co-pays or deductibles) or treatment limits (e.g. number of visits)



for mental health services cannot be more restrictive than limits for medical/surgical benefits (ASHA, 2011).

Maryland, New York, Oklahoma, and Tennessee have limited autism mandates. In general, these mandates focus on medical conditions. Insurers cannot deny otherwise available coverage simply because treatment is used to diagnose or treat autism spectrum disorder. Coverage for treatment related to autistic disorder is restricted and only available for a child under age 18 or 19, depending on the state (ASHA 2011).

Almost half of the states have broad autism mandates that delineate coverage for assessment, diagnosis and treatment of autism spectrum disorders. These states are Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, Oregon, Pennsylvania, South Carolina, Texas, Vermont, and Wisconsin. In five of these states - Kansas, Massachusetts, Missouri, Nevada, and Vermont - the mandates became effective January 1, 2011 (ASHA, 2011).

Consistent with the documented importance of early intervention (Chasson, et al., 2007; Jacobson, et al. 1998), the mandates in these states target provision of services to young children. In South Carolina, for example, an individual must be diagnosed with an autism spectrum disorder at age eight or younger to be covered. Texas sets the age of diagnosis at age nine. Coverage is typically limited to those aged under age 18, although Illinois and Pennsylvania extend coverage to age 21.

With a few exceptions, state mandates cap benefits at \$36,000 per year. Kansas reduces the cap for children age 7 to 18 from \$36,000 to \$27,000 per year. Kentucky made a distinction between large and individual / small group health benefit plans. Benefits in large group health plans were capped at \$50,000 per year for children age 1 through their 7<sup>th</sup> birthday and \$1,000 per month for children age 7 through 21. In individual and small group health benefit plans, the cap was set at \$1,000 per month per covered individual. South Carolina capped behavioral therapy coverage at \$50,000 per year. Two states set lifetime dollar limits on coverage. In Louisiana, that limit is \$144,000. In New Mexico, it is \$200,000 (ASHA, 2011).

#### **4.3.1 Effect of mandates**

Since state Autism Mandates are still relatively new, it will take time to see their full effect. In the short run, though, it is clear that mandates increase premiums. Whether the increase is problematic is debated. Critics argue that premium increases create loss. Some portion of individual policy holders will drop coverage because they can no longer afford to pay the premiums. The cost of paying claims would then be spread over a smaller pool of policy holders. If individuals leave the insurance market, a majority of remaining policy holders would be employers. It is argued that higher premiums would pass to workers in the form of lower net wages or loss of employment. Results of empirical studies of these expected effects have been inconclusive, however. (Boulder, et al., 2009; Collins et al., 2005, Hopkins & Zweifel, 2005, Klerman & Goldman, 1994, Sommers, 2005, Wolaver et al., 2003).

Actuaries with The Council on Affordable Health Insurance estimate an autism mandate will increase the cost of health insurance by about 1 percent, but caution that increasing prevalence rates coupled with coverage of more services could drive premiums up 1 to 3 percent (Bunce, 2009). But, autism is only one of many mandates that state legislatures imposed on insurance providers in recent years. Between 2004 and 2010, the number of insurance mandates for all types of issues across the states rose 18% from 1,823 to 2,156.

Taking the broad spectrum of mandates into consideration, actuarial estimates of aggregate premium increase runs between 10 to 50 percent (Bunce, 2010). Currently, Rhode Island has the largest number of mandates at 69, whereas Idaho has the least at 13 (Bunce & Wieske, 2010). The total cost of meeting all mandates rather than the marginal cost to meet an autism mandate needs to be considered.

Advocates of autism mandates concede that premiums increase, but they take a human capital investment perspective and argue that monies spent in early intervention will be repaid later in the form of reduced expenditures to care for those with ASD. There is research supporting that perspective. Jacobson et al, (1998) conducted a relatively early cost/benefit evaluation of providing early intensive behavioral intervention (EIBI) for children with ADS aged 2 to 5, using representative cost data from Pennsylvania. Their model assumed EIBI could have three potential outcomes. Some children would be able to engage in regular classroom instruction without support once the intervention ended. Other children would still require special education. Some children would need intensive special education. Given the range in treatment effectiveness and expected outcome, they estimated that cost savings in constant dollars would range from \$187,000 to \$203,000 (\$263,670 to \$286,230 in 2011\$) per child for ages 3 to 22 years and from \$656,000 to \$1,082,000 (\$924,960 to \$1,525,620 in 2011\$) per child for ages 3 to 55 years. Given initial costs of \$33,000 to \$50,000 (\$46,530 to \$70,500 in 2011\$) per year for EIBI, they argue that although EIBI would have a modest effect on cost-benefit balance in the short run, cost in the long run would be greatly outweighed by potential savings.

In a similar vein, Chasson et al. (2007) compared costs associated with 18 years of special education to cost to implement 3 years of Discrete Trial Training as an early intervention in Texas. They estimate that by implementing 3 years of early intervention, the state of Texas would save \$208,500 (\$223,095 2011\$) per child across 18 years of education. Given a conservative estimate of 10,000 Texas children with ASD, they estimate overall savings of EIBI would be \$2.9 billion (\$3.1 billion 2011\$).

## 5. Health care reform

In 2008, President Obama made a campaign pledge to support a federal mandate requiring coverage for autism treatments. On March 23, 2010 he signed the Patient Protection and Affordable Care Act (PPACA). Seven days later, PPACA was amended by the Health Care and Education Reconciliation Act of 2010.

PPACA introduces significant change in the health care market in the United States. The law places new requirements on individuals, employers, and health plans regarding possession and coverage of health insurance. The law also restructures the private health insurance market, sets minimum standards for health coverage and provides financial help to certain individuals and small employers to secure health insurance (Fernandez, 2010).

State exchanges will be used to offer a variety of health care plans. Each plan must offer a package of "essential benefits" as outlined in the Affordable Care Act. Of interest to the autism community is inclusion of mental health and substance abuse disorder services, including behavioral health treatment as well as preventive and wellness services and chronic disease management in the so-called "essential benefit list".

The autism community sees the new law as a win as it will reduce or eliminate opportunity for health insurance companies to impose pre-existing condition exclusions, excessively long waiting periods before coverage begins, or rescissions of coverage.

Further, ability of insurers to set annual or lifetime caps on coverage will be limited (Autism Speaks, 2011b).

Still, these changes may not go far enough. Not all health plans will be bound by the new law. The only plans required in 2014 to cover essential benefits will include plans offered by state-based exchanges where individuals and businesses purchase coverage, and plans offered in the individual and small group market outside the exchange. Existing coverage, plans offered in large group market outside of the exchanges, and self-insured plans will not be required to supply the essential benefit package to the insured. Thus, in many ways, the new law does not move far beyond the state mandates already in place.

Those state mandates were due, in large part, to the lobbying efforts of Autism Speaks, a large autism advocacy organization. Reviewing provisions of the new law as they related to the autism community, Autism Speaks, still saw room for improvement, reaffirming a commitment to state and federal lobbying efforts to “make effective health care coverage a reality for the autism community and to bring about an end to discrimination of individuals with autism by the insurance industry.” The group does not see health care reform ending the problem of high medical costs for a child with autism, though the law may lessen the severity of those costs. Consequently, they will continue efforts to “make autism insurance reform a reality for all Americans living with autism” (Autism Speaks, 2011b).

## 6. Future considerations

It is clear that, in the future, attention must turn to study of ASD-related issues in a global context. Epidemiological studies conducted since 2000 confirm ASD is found worldwide. For example, according to these studies, the estimated incidence of ASD in children is 4.3 to 5.5 per 10,000 in Australia (Williams et al., 2005), 4.5 per 10,000 in North America (Barbareis, et al., 2005), 5.9 per 10,000 for Chinese children in Hong Kong (Wong & Hui, 2008), 8.3 per 10,000 in the United Kingdom (Powell, et al., 2000), 8.6 per 10,000 among the Danish (Lauritsen, et al., 2004), 18 per 10,000 in Saudi Arabia (Yazbak, 2004) and 27.2 per 10,000 in Japan (Honda, et al. 2005).

Recently, in the first comprehensive study of autism prevalence in a total population sample, an international research team estimated the prevalence rate of ASDs in South Korea at 1 in 38 children (Autism Speaks, 2011c). Taken together, these figures indicate that a significant portion of the world’s population faces the challenges of ASD and will continue to do so in the years to come.

Despite growth in epidemiological studies such as these, the specific percentage of persons with ASD that could benefit or have benefited from education, medical, and social services in developed or developing countries is not known. There are several reasons for this lack of knowledge. It is challenging to establish diagnostic criteria that are consistent across countries. Diagnostic criteria are behavioral rather than biologic. Cultures can differ in behavioral social norms such as eye contact or expected timing of speech development, making it difficult to identify autism-related behavior (Daley & Sigman, 2002; Naqvi, 2009). Culture can also influence views of behavior, perceived need for treatment and the type of treatment offered. For example, in a study of incidence and treatment of ASD in China, Clark and Zhou (2005) report that only in the last ten years has autism been broadly recognized among Chinese service providers. Few Chinese professionals are trained in the diagnosis and effective treatment of ASD. The small number of treatment programs that exist are only found private schools and hospitals in large cities. Traditional Chinese

medicine sees autism as a “Yin” disorder displayed in social isolation, lack of communication, and apathy. Herbal medicines, acupuncture, and relaxation are common treatments. Only rarely do children on the autism spectrum receive sensory integration training or applied behavioral analysis. No formal education programs exist for children with autism in China.

Another issue that limits accurate count of those with ASD is that knowledge of behavioral indicators may be limited, especially in developing countries (Naqvi, 2009). Even when individuals with ASD have been identified, access to services is a function of public and private resource levels and these levels vary widely across family, as well as across country and culture. An additional factor is that, although there is general agreement among professionals that early therapeutic intervention helps children improve communication and relationship skills, it is also recognized that not all children respond to therapy and, among those that do, gains are not equal (Canadian Institutes of Health, 2007). Currently, even in developed countries with a long history of providing ASD-related services, no mechanism exists to coordinate service delivery or track level and outcome of service use. These limitations will need to be addressed and overcome before the efficiency and effectiveness of ASD service delivery in the global community can be improved.

Much remains to be learned regarding public and private costs of diagnosis and treatment as well as cost of lifetime care for those on the autism spectrum in the global community. Of necessity, much of the data in this chapter has come from the United States and other developed countries, as that is where the vast majority of research on autism related costs has been conducted. But, the costs associated with treatment and care of someone with autism have no cultural bounds.

Initial research on autism diagnosis and service delivery in developing countries suggests that diagnosis can be a cumbersome and frustrating process, access to effective therapeutic services is often limited to nonexistent, and the greater part of the burden of care rests on family members (see, for example, Al-Salehi, et al., 2009; Daley, 2002; Mendoza, 2010; Tuman, et al., 2008). More research is needed within countries to determine the most effective and efficient means to improve diagnosis and service delivery in the context of a given country, culture, and governmental structure. In addition, research is needed across cultures to better understand the types of ASD-related needs and costs that transcend culture as well as to compare care models in an effort to build a set of best practices.

Development of effective means of information sharing across culture is critical in the quest to improve efficiency and reduce costs in programs, education, medical, and social services. To build a foundation for research, screening along with diagnostic instruments and processes need to be standardized across countries and cultures, while attending to cultural relevance and sensitivity when translating the instruments used. To strengthen the science underlying treatment recommendations, treatment modalities need to be vetted both across cultures and across various populations within cultures. Fortunately, advances in computer technology, Internet access, and electronic data storage and management systems make sharing of information much easier and cheaper now as compared with times past.

To help achieve these ends, Autism Speaks, an autism advocacy group in the United States, has recently launched two coordinated efforts. In 2002, Autism Speaks began development of the Autism Epidemiology Network in collaboration with the United States Centers for Disease Control and Prevention. The long run goals of this effort are to develop a network that facilitates exchange of information and research collaboration on epidemiological



activities across countries, to draw on successful international collaboration models that have been applied to other health conditions as a way to identify best practices, and to foster use of epidemiology as a tool for understanding the causes of autism through making comparisons across diverse genetic, environmental, social and cultural situations.

In 2008 Autism Speaks formed an international collaboration with North, South, and Central America for autism-related research and service training. The international collaboration has a four-fold purpose. First, it is to increase public and professional awareness of autism spectrum disorders outside the United States. A similar campaign in the United States has been instrumental in building support for passage of state and federal legislation focused on improving research and services. Second, it is to develop and validate screening and diagnostic tools that can be used across cultures. Tools such as these enhance cross cultural comparisons and can improve the ability of researchers to identify possible causes of ASD. Third, it is expected that collaborative research will be facilitated through the sharing of epidemiologic ideas and practice. To date, close to 80 researchers representing over 30 different countries have engaged in collaborate research under this initiative. Finally, the collaboration strives to build service capacity by providing professional development, technical assistance, content development, and education for service providers (Autism Speaks, 2011a).

Expanding the collaborative efforts that Autism Speaks has made to facilitate research development to include additional countries will be an important step in improving diagnosis and treatment of ASD worldwide. In addition, methods of information exchange developed in the research, diagnostic, and service provider training communities could serve as model for efficiently and effectively connecting families with a child with autism with service providers, including medical personnel and educators, as well as community, insurance, and social service agencies.

## 7. Conclusion

Research on expenditures related to ASD underscores the fact that the disorder imposes high costs on immediate family as well as society. Families of those with ASD shoulder a large part of the burden of ASD-related costs, especially in developing countries where few public or community resources exist. Not only are there direct costs such as dollars out-of-pocket for therapy and medical care not covered by insurance, there are also the indirect and intangible but no less real costs of lost opportunity, reduced productivity, attention largely focused on the child with ASD to the exclusion of other family members, increased stress, and a forever changed family structure.

Persons with ASD benefit from education, medical, and social services. But, the question of how to allocate payment of these services between the public and private sector is ardently debated. Neither sector has unlimited resources. Research is an important means of finding effective ways to lessen the burden of ASDs. Certainly, more needs to be learned regarding the cause of autism and reasons for the diversity in the presentation and progression of the disorder. Given limits to both private and public resources, scientific study designed to identify which interventions and therapies are most effective in helping a child with autism learn, develop, and become productive are necessary. Reasons why certain therapies work with some children and not others need further investigation. Although ABA is currently considered the behavioral intervention with the greatest support from the scientific community, there is still much debate about its efficacy. More studies of different



therapeutic interventions that follow strict standards of scientific inquiry are needed. Longitudinal studies would be particularly useful in judging the long term benefits of various types of interventions for ASD. Ways to improve efficiency and reduce cost in program delivery also need to be evaluated.

Recent increase in the number of Medicaid autism waivers and state autism mandates in health insurance as well as the coming implementation of health care reform offer researchers a rich source of natural experiments in determining the effects of change in public policy on the welfare of persons with ASD. Research in ASD-related cost could benefit from taking a systems perspective and investigating how the various sectors that serve those with ASD might collaborate both to enhance service delivery and reduce costs. For example, a child whose digestive problems are eased by medication will likely be a better learner. A child who learns through behavior therapy how to express and resolve frustrations may be able to reduce behavior modifying medications. Other types of synergies may exist as well.

In the public policy arena, cost/benefit analysis of programs and policies designed to help families with a child with autism is needed to inform resource allocation. Programs and agencies exist that can help families that have a child with autism, but there is little coordination of effort among these. Further, current programs and policies for those with ASD can fall short of meeting the pressing needs of families. Resources available to families can be location specific. Differences in state administered Medicaid programs and state insurance waivers can create some dramatic inequities between residents of different states. Recently, media highlighted the situation of two families. One family lived a state without an autism insurance waiver and paid \$1,000 per week for behavior therapy. The other family lived in a state where an autism insurance waiver required health insurers to cover costly behavior therapy. They paid \$3,000 per year for the same type of therapy (FoxNews, 2008). Ways to reduce such inequities need to be sought.

Looking to the future, today's young child with ASD will become tomorrow's adult. At least some portion of high functioning individuals with ASD could be employed, but they will likely need help mastering the technical and communication skills needed to obtain and retain employment. Family support for individuals currently receiving home care must inevitably decline either through drain on family financial resources or the aging and death of parents who have been the main caretakers. Options for these individuals need to be considered now.

Rising numbers of individuals with ASD and the high cost of their care make it important to continue to press for advances that will provide genuine help for these individuals and their families. Coordinated efforts from a variety of sectors including medical, educational, research, community, insurance, public policy is needed. Much remains to be learned about how best to invest today in the development of children with ASD to create a better future for them, their families, and society.

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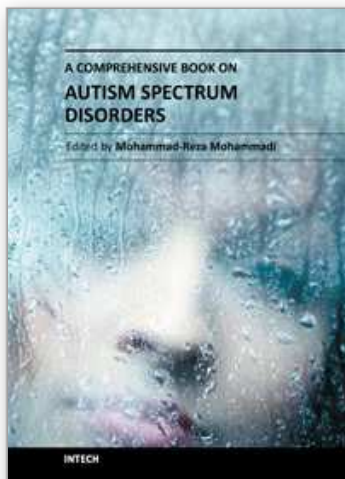
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## **A Comprehensive Book on Autism Spectrum Disorders**

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The aim of the book is to serve for clinical, practical, basic and scholarly practices. In twentyfive chapters it covers the most important topics related to Autism Spectrum Disorders in the efficient way and aims to be useful for health professionals in training or clinicians seeking an update. Different people with autism can have very different symptoms.Â Autism is considered to be a “spectrum” disorder, a group of disorders with similar features. Some people may experience merely mild disturbances, while the others have very serious symptoms. This book is aimed to be used as a textbook for child and adolescent psychiatry fellowship training and will serve as a reference for practicing psychologists, child and adolescent psychiatrists, general psychiatrists, pediatricians, child neurologists, nurses, social workers and family physicians. A free access to the full-text electronic version of the book via Intech reading platform at <http://www.intechweb.org> is a great bonus.

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