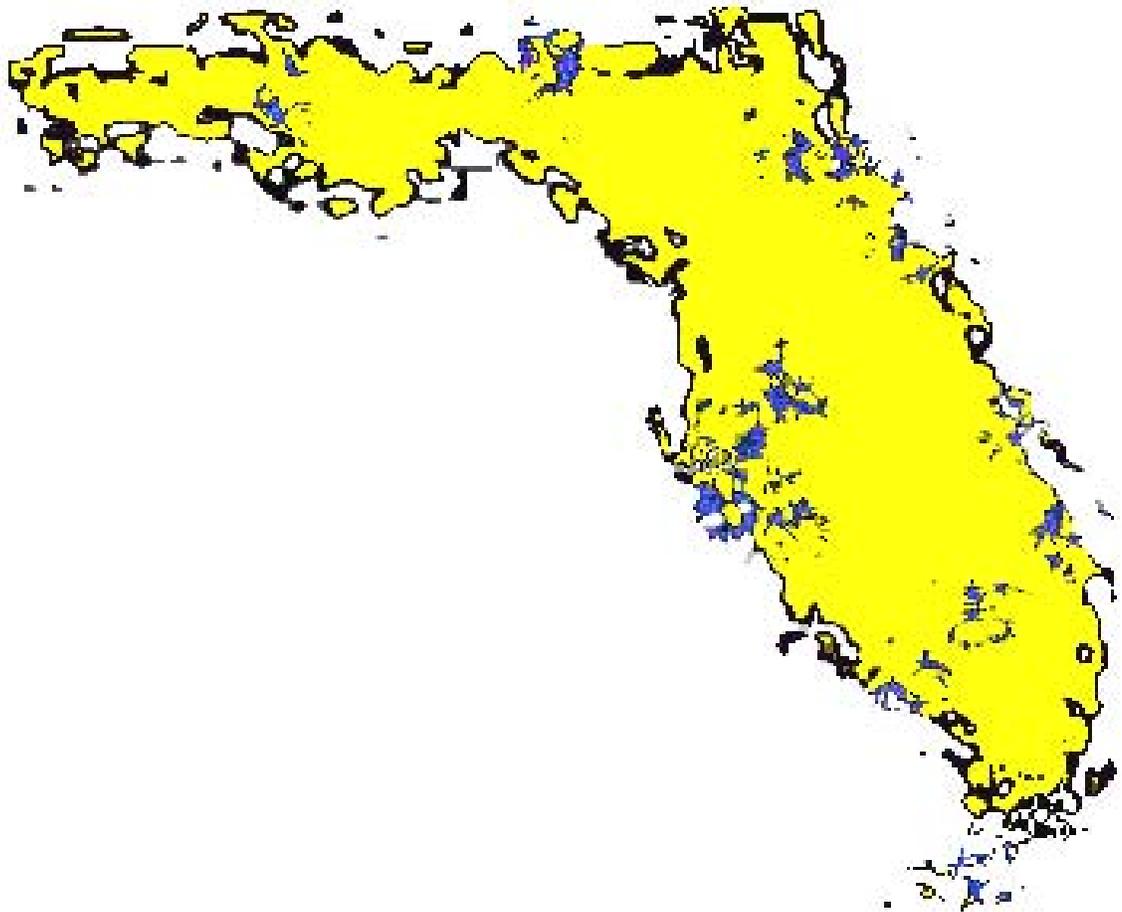


How **BRIGHT** is the Sunshine State  
when it comes to Autism?





**How Bright is the Sunshine State When it Comes to Autism?**

**Students of Cohort 23**

**FIU Pines Center**

**Weekend BBA Program**

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## **Executive Summary**

The purpose of this research paper is to define the problem that Florida has with providing the necessary care that those with autism require. A strong early intervention program coupled with appropriate therapies and medical treatment will give autistic children the opportunity to live full, productive lives; and not be dependent on society for their adult care. The only wish of parents with autistic children is to give their children the life skills they need so as not to be a burden to society. “All we want is to be able to train them to function in a normal way without becoming a problem for society in the future “(A3).

There are cases where parents must abuse the loopholes in the system just to provide the most basic of care for their children. She is legally divorced from her husband so that Richard [her autistic son] might be able to receive Medicaid (A10).

By ignoring this problem, Florida faces an economic catch twenty-two. The children who are allowed to grow up as non-functioning adults will become a burden to the social service system for the remainder of their unproductive lives, but will have their parents in the workforce. Conversely, those that receive the training and education they deserve are given so at the expense of their parents’ livelihood; the state loses the benefit of being able to employ the parents of autistic children. Florida will help its citizens by giving autistic children the opportunity to work as adults and allowing parents of autistic children to reenter the workforce.

The state has done a commendable job of providing money for autism research. Sixteen states have already passed legislation to improve how autistic people are treated; however, Florida lags behind other states in the way it handles autism. Insurance companies that provide

coverage in Florida are not obligated to treat autism as a physical condition, but a mental one. Many states require that autism be given the same parity as physical conditions in regards to coverage (table B7).

As a society, we have an obligation to provide every citizen the opportunity to realize their full potential. Insurance companies that wish to offer coverage in Florida must provide equally for everyone. People with autism are discriminated against due to the higher average cost of care over their lifetime. This is done solely to enhance the bottom line of large insurance companies who are interested in cutting costs rather than helping those who need it.

This problem is not limited to the United States. In our research, we have learned that many nations face this problem. However, it is not an entirely fair comparison since many of these countries provide a universal healthcare system to their citizens. This does prove that the world sees autism as a rapidly growing problem that will not improve without intervention.

Florida can use the format of legislation from proactive states that have already been successful in creating a better situation for those with autism. The legislature must act now before this issue becomes a crisis. As indicated in (chart B4), the rate of growth in autism far outpaces any other disability. Florida's economy does not possess the resources to provide a lifetime of adult services to every autistic person that did not receive help as a child. It has been shown that a comprehensive early intervention program will be more cost effective in the long run (table B7). The legislature must enact a law now to avoid passing this worsening problem to future generations.

One of our objectives is to have autism and all related disorders defined as a medical condition subject to coverage from an insurance company. Requests for applied behavioral

analysis (ABA) should be viewed as a medical necessity; and should be provided for no less than thirty (30) hours per week for two years for children between the ages of 2-6 years old.

Occupational and speech therapies should be covered by an insurer or provided for adequately by a child's Individual Education Program (IEP) once they enter into the school system. Physical therapy should be covered as a medical necessity. Florida's Centers for Autism and Related Disorders (CARD) should be provided a level of funding commensurate with the growth in the rate of autism cases (Chart B4).

What follows are personal stories from families that have children with autism. They detail how their lives have been affected by the lack of coverage available to their children; and how they have had to sacrifice personal income so their children do not become a burden to the state in adulthood.

### **Ciel Marie's Story**

Ciel Marie is a gifted six year old girl who attends a regular public school and was promoted to kindergarten in May 2007. She was born in Miami, Florida and lives with her parents, her 13 year old brother, and four year old sister. Ciel Marie speaks English, Spanish, and French. Ciel's mother had a full term pregnancy with a natural delivery. She reported that at eighteen months of age; Ciel Marie stopped talking, cried all the time, covered her ears, and also used to hide inside of the house. When she took Ciel to her pediatrician, the doctor told her Ciel was going through "the terrible twos". When she turned two years old, Ciel's mother decided to take her for a speech therapy evaluation. She also took her to Early Intervention to get a precise diagnosis. After a four hour evaluation, Ciel Marie was diagnosed with autism spectrum

disorder. They reported the Ciel's brain was like that of a six month old baby. This was devastating for the family; their lives changed completely.

They started by looking for the best neurologist in town and found that Dan Marino has a foundation that supports families with autistic children. Ciel Marie received 26 hours a week of therapy for about two years. Ciel Marie did not have any insurance; however, she qualified for Medicaid benefits for three months. Ciel's mother applied for Health Kids, and her daughter was approved to receive occupational therapy for only one year. Ciel is currently not receiving therapy.

Her improvement has been incredible. She only takes supplements to control and prevent fungus growth in her intestines, as well as inflammation in her brain. The supplement does not need to be prescribed by pediatrician. Ciel's family has had to refinance their house three times already to come up with the money for Ciel's expenses. Credit cards have been another resource to pay for their daughter's expenses. Ciel's pediatrician is located in Jacksonville, FL and he charges \$390.00 per hour. Ciel Marie receives counseling for anxiety every week at a cost of \$45.00 per session.

Ciel has improved to the point that she only needs to see her pediatrician every six months; this trip costs the family \$1,200.00. The family thanks God because their daughter is a miracle. They have been through so many trials after Ciel was diagnosed with autism.

## **A Family in Crisis**

I spoke with an over worked woman who seemed to be stretched to the limit by trying to juggle all of her obligations between caring for her autistic son, working full-time, and trying to convince her husband to be a part of their son's life. In the interest of protecting her privacy, I will refer to this woman by the name of Claudia, her husband James, her daughter Olivia and her son Adam.

Adam was diagnosed with Applied Behavioral Analysis (ABA) at the age of four. Although Claudia has been very private regarding her son's condition, she agreed to speak with me regarding the impact that this is having on her and her family.

Since Adam's diagnosis, his father, James, has withdrawn from him. James' inability to accept and unwillingness to work with Adam has placed a huge amount of pressure and responsibility on Claudia. "At times, I feel like he (James) doesn't even accept Adam as his son," Claudia shamefully confessed.

Claudia states that the financial burden doesn't make things any easier either. Adam receives regular treatment for ABA that is not completely covered by his insurance. Claudia says that her greatest challenge regarding her career is that she has to make enough money to support Adam and somehow maintain a job that allows her the flexibility to care for him.

Throughout our interview, Claudia spoke more about her husband James. His lack of interest in assisting Claudia in caring for their son has created an incredible amount of strain and tension in their home. She recounts how when they first got married, James constantly spoke about having a son. Their first child was a girl, Olivia, so the couple tried again and Adam was born. James was so excited when he learned that he was going to have a son, and according to

Claudia; now his happiness has turned into resentment. James refuses to talk to Claudia about his feelings regarding his son and he doesn't address her concerns about his lack of support. Claudia states that James showers their daughter, Olivia, with love but, it was almost as if Adam doesn't exist. I asked Claudia if James would mind talking to me, and I was not surprised when she said no.

Claudia's frustration mounts as she tries to deal with her husband's resentment while trying to do what's best for Adam. She mentioned how she has thought of leaving her husband, for what she considers to be neglect, but she said that she honestly cannot afford it. For now, Claudia accepts her husband's neglect and continues to fight for her son's health.

Autism is a huge strain on the family and the child who is suffering from the disease. This is a true example of how families are impacted by big business decisions. The insurance companies do not provide enough coverage and the families are sacrificing in every way imaginable to support their loved one. Perhaps a little more intervention from the government and a lot more support from the insurance companies will ease the tension, resentment, and enormous stress that these families are forced to endure.

### **Chris and Kevin**

The family I interviewed resides in Tampa, Florida. The household members are: Sam, the dad, Wendy, the mom, oldest son, Chris, and the youngest son, Kevin. This family has been blessed with two wonderful, healthy boys; both of whom have autism.

I asked Sam and Wendy, "What was their greatest challenge dealing with autism?" They looked at each other and with a firm resignation on their faces, smiled and responded, "We take

one day at a time, then one problem at a time and...” the father continued, “more than one bill at a time.”

From what I depicted in her voice, she was holding back the tears. They have been dealing with this situation without any real help for many years now, and their biggest fear is who will carry on when they are gone. Sam and Wendy also decided to not have anymore children in fear of not being able to provide for a newborn or for Kevin and Chris.

They wanted to communicate the need that exists amongst families with such a challenge, and how it was never meant to be their choice but, a draft from above. This family is doing well because both parents are together and rely on each other for emotional support. What follows is in Wendy’s own words.

*My oldest son Chris, was diagnosed with autism spectrum disorder (ASD) at the age of three; he is now 17 years old. My second boy is 15, and from the minute he was born he was put under my microscope; it is a mother thing you know. I did not want to miss any time with my second son and I was able to recognize many signs immediately. The same signs were there as with Chris, but I did not know any better. I just went on avoiding situations and outings that would bring about tantrums.*

*My mother-in-law took care of our kids in order for me to keep working; we needed both incomes to make ends meet. From the pediatricians to the pre-k teachers, I think they knew what was going on. It is just as hard for them to label our children, and we as parents don’t want to believe there is anything wrong with our children. There is a struggle*

*within us. There was not much medical or educational information at the time, at least not for me. No one in our family history had this challenge, and there was plenty of criticism from family, friends, and even strangers who thought I did not know how to raise my kids. At times, I felt unfit, and that is when we decided to form a new circle of friends; those who were walking the same path or that were knowledgeable about autism, and would understand my children's uncontrollable reactions. We never had a defined treatment and had to investigate about different therapies through other families that had already faced these problems.*

*All the tests were paid out of our pocket, and there was always some new treatment to try; we are always looking for a cure or answer. We knew in our minds that this would be a lifetime process, but in our hearts we kept the hope of a new therapy, or medication that could reverse it. We paid for everything out-of-pocket. I left my job and my husband cut his business trips; he cannot stay away overnight anymore. We live on a budget and our income barely covers all of our expenses. One child is low-functioning, the other high-functioning; that also makes a difference because the high-functioning one has no coverage and there is very little help for the low-functioning child.*

*We need help! Our government needs to recognize that my family has a financial burden of over \$25,000 a year for one child alone, and Kevin also needs attention and therapy even if he is a milder case. We are on a fixed, one income budget; this limits the help we can afford for our children. All*

*we want is to be able to train them to function in a normal way without becoming a problem for society in the future.*

*Please thank your fellow students and the University for what they are doing to help raise awareness to this cause; in the long run, we will all benefit.*

### **Steve's Story**

Nidia a resident of Orlando, Florida has two children; a five year old son named Steve and a ten year old daughter named Stephanie. Steve was diagnosed with classic autism (Kanner's Syndrome) at two and a half years of age. Before his diagnosis, Steve did not display any symptoms of autism. Steve's diagnosis was unexpected and shocking. At the time of his diagnosis, there was no medical or educational information about autism. Nidia was left to take on a life long battle with autism without any information or any help. The only help she received was a suggestion from the pediatrician who diagnosed Steve. He recommended Applied Behavioral Analysis (ABA) to be one type of treatment that would help alleviate Steve's condition. Financing these treatments soon became a worrisome burden as the costs to rehabilitate Steve became and continued to be overwhelming. Nidia's yearly expense to have her son attend a school that applies ABA therapy is \$35,000 per year and increases annually.

The economic, emotional, and psychological strains this condition puts on Nidia and her family are crushing. Steve will greatly benefit from the behavioral and speech therapy, but due to insufficient health insurance coverage and the high price of these treatments, Nidia is forced to deny her these opportunities. Furthermore, due to Steve's condition, she must stay at home and

care for him relying solely on her husband's income to support her family.

Currently, Steve is enrolled in a school for autistic children that applies ABA, and also has social behavior, occupational, and speech therapies. Unfortunately, due to mounting financial difficulty, lack of insurance coverage, and the absence of legislature for those affected by autism, Nidia's child is not able to continue to benefit from these therapies. Nidia is restricted to the basic therapies her husband's income can afford. Steve receives basic behavioral and speech therapy at ABC School House and her son has improved. After participating in 40 hour per week for almost three years using ABA techniques, Steve is showing tremendous behavioral, social, and speech improvements. The individual attention of professional therapists has helped Steve to become more adaptive and functional in society with hopes of one day becoming independent. However, if these therapies are discontinued, Steve could very well regress and become incapable of supporting himself in the future.

Parents of autistic children are largely burdened with troublesome rehabilitation costs. They encounter many financial and legal roadblocks in their path towards the wellness of their child. Steve is fortunate that his parents can afford to grant him satisfactory access to a school designed for the rehabilitation of children with autism. Nevertheless, the treatment Steve is receiving is insufficient. The inadequate insurance coverage, absence of legislature assisting those affected with autism, and lack of social programs offered by the government are to blame. Nidia and many advocates for autism awareness deem it necessary and critical that the government intervenes. It is imperative that Florida take a progressive role in treating autism.

## **Robin and Patrick**

On May 18, 2007, I had the pleasure of speaking to Robin and learning about her son, Patrick. Patrick is the youngest of Robin's three children; Douglas 14, Diego seven, and Patrick five. Patrick was diagnosed with autism at age two. Robin had always sensed that Patrick was different than her two other boys, but none had diagnosed her child in any way, much less with any type of disability.

One day while visiting a pediatrician for one of her other boys, she asked him to take a look at Patrick to see if he could determine why she felt Patrick was different. Within a few moments of examining Patrick, he realized he might have had some deficiencies. He then recommended that Patrick should be seen by a professional and have tests performed. After a grueling three hour examination, Robin was finally given the diagnosis she had been afraid of; Patrick was autistic. Robin now believes that Patrick could have been diagnosed at eighteen months, but because she was already a mother of two, any concerns she would bring up in regards to Patrick were disregarded because the pediatrician would tell her, "You cannot compare your other children to Patrick, every child develops differently."

When Patrick was diagnosed, the doctor gave Robin educational information and sent her to the early intervention program provided by the state of Florida in addition to the Debbie Institute in Miami that specializes in autistic children. Robin believes the greatest challenge for any parent dealing with an autistic child is the financial burden. This burden is inherently due to the inefficiencies of the government in providing adequate relief and resources for autistic children. Currently, Robin has Blue Cross & Blue Shield PPO and they provide a mere \$500 per year for speech therapy; speech therapy is currently \$150 per hour. Her son also requires many

hours of ABA and occupational therapy. The ABA treatment lasted for 2 and half hours a day for one year and cost Robin \$40,000. Clearly, there is a deficit of funds available for Patrick's therapy and other children suffering from autism.

Robin believes it is imperative that Florida increase funding for autistic children. Although she hopes that an intervention by the government will be enacted by future political leaders, she has taken a pro-active approach. Robin has established a not-for-profit organization called "Faith's-Place" in Miami Springs, FL. This organization provides reduced pricing for parents and offers free therapies to the children of families that cannot afford to pay. She currently has the support of Poinciana United Methodist Church, which offers her use unused spaces within the church to conduct therapeutic sessions with autistic children. The church is receives 10 percent of the group's revenue. This story does have a happy ending. Patrick is very close to full integration with normal children in school and is nearly as independent as any other five year olds. This is the result of three years of professional intervention and the support of a loving and devoted mother. However, not every child is so lucky. Very often, children affected with autism run the risk of being left behind. In order for less fortunate parents to afford these treatments for their children, the government needs to provide more aid to these families. Only then will all parents with autistic children be able to provide the same opportunities that Robin was able to provide for her son.

## **Christian's Story**

The out-of-pocket cost for children with autism is extremely expensive; for a family of four, the situation may be a little difficult. Without the income of both parents in this family, supporting their son with autism would be impossible.

*“My second son was born on January 30, 2001, but it wasn't until four years later that he was diagnosed with Asperger's Syndrome. Since that moment, the cost of therapies, behavioral medicine, and neurologists made us change our lives. We put our family into \$10,000 to 15,000 of debt per year, and lie about being separated in order for me to support the needs of my son.*

*Every three months, I pay \$1,152.00 in out-of-pocket medical expenses that the health insurance will not cover; the cost of the neurologist every two months is \$350.00 and the deductible for the speech therapy is \$48.00 three times a week.*

*My family has been a strong support in raising my son, and is the only reason I can still work to cover out-of-pocket expenses. Being a full-time employee and, with summer around the corner, I recently found out that the summer camp will cost \$340.00 a week. Again, I will need all the help I can get to move on and afford to give my son and my family a decent life.*

*Every day the situation gets harder to endure, and I constantly find myself wondering, “What else I can do to help my son? How else can I do it? Who I can go to for help?” I feel that nothing can ever happen to me,*

*because I need to live a 100 years in order to take care of my son. My only hope is that with the growing number of children with autism, the cure is soon on its way and the help my son needs is just a couple of experiments away.*

*Supporting my six year old son has not been an easy journey, but the most rewarding events in my life are seeing him learn, talk and sing. I know he may not live a normal life, but I'll make sure he lives this life as happily as possible, and I will provide everything he may need."*

For many parents in this situation, it is very difficult to focus their entire life on just one child; and the fact that they will never be able to enjoy their children's weddings, graduations, or living an independent life. For many parents, the situation is like living in a bubble. It is financial and marital destruction for the possibility of a better tomorrow.

## **Harry's Story**

I had the opportunity to interview a very strong woman whose son, Harry, is ten years old. He was diagnosed at the Mailman Center of Jackson Memorial Health System in Miami, FL, with high functioning autism at the age of 21 months. Harry's mother states, "Looking back I remember the little things that weren't quite right before the diagnosis." Due to the fact that she had a daughter prior to Harry, she noticed that Harry would turn lights off and on in the house and constantly run water in the bathroom as if he was obsessed.

In order to find out more information about autism, Harry's mother was forced to take a proactive approach to seek out insurance coverage for all the different types of treatment. Harry had the opportunity to attend Program Easterfield in Miami that offers different therapies and education for young children with disabilities until the age of four. The treatment was covered by the Mail Handlers insurance at that time. This gave Harry the opportunity to socialize and develop the skills that were needed for a child of his age; there was a tremendous difference in his behavior. Harry's mother had to quit her full-time job because of the extensive attention that her son needed child needs with all the different therapies. Her family income of \$60,612 fell to \$34,829 because she had to quit her job as a police officer.

Harry is currently covered by his father's Humana Health Plan. Harry's parents are not eligible for Social Security Benefits for Disabled Individuals due fact to the fact that his father's income is too high.

Now that Harry is in the fourth grade, he has been streamlined in the Broward County Public School, where he attends a regular class with more than twenty students. There is a teacher's aide for Harry and another autistic student. The School Board provides Harry speech and physical therapy twice a week through his Individual Educational Plan (IEP). She meets semiannually with a Case Management Coordinator to be issued a Medicare Waiver. The waiver covers behavioral analysis, for four hours a week and respite care that gives the parents a break by having a representative come in for one or two hours to watch Harry. Harry's mother believes this is not the direction she feels that her son should go; the state should pay for socialization skills with other children with disabilities. In her opinion, "The State of Florida is way behind in the services they offer for children with autism, as well as what they cover." This

has caused her to consider relocating to South Carolina that offers help and services above and beyond what Florida offers for children with autism.

Their greatest fear is that they will not be alive long enough to make sure that their child is safe and have the abilities to function independently in society. Harry's parents spend about \$500 to \$700 a month for therapy and special needs;

- Eczema treatment by a dermatologist
- Primary doctor visits
- Extra costs for sedation dentistry
- Tutoring for six hours a week for reading comprehension due to being streamlined in public school
- \$125 per week for summer school care at the YMCA

Harry's parents have not considered medication to assist with his behavior, but might consider that in the future. Harry's mother knows that she might have to fight for better coverage for her son. She has not pursued more assistance from the Miami-Dade County School Board, but might look to do this in the future with Legal Services.

### **Donna's Story**

*"At the age of 18 months Donna was diagnosed with low functioning autism, which was a total surprise to my husband and me. Being my first child, I felt it was my fault and the scariest part was I didn't even know what autism was. The doctors were talking so fast and short that my understanding of autism*

*was not clear. Two years later, I pushed myself to understand my child's neurological disorder and began to evaluate my options for treatment.*

*"I had a full-time job as a paralegal for a law firm earning \$27,000 a year, but due to my daughter's special needs, I had to stop working. I have been able to find odd jobs here and there, but nothing to really cover all the costs associated with therapy for autism. My husband's income currently supports my family and through his employer we are insured by Cigna.*

*"Before we enrolled Donna in a special need school, she could not speak or barely communicate with us. She has undergone some drastic changes during her attendance at this school. Unfortunately, due to her age, we will have to find another school for her to attend. This will probably be a public school due to the enormous cost associated with a private school. My husband and I are very concerned with the treatment options available at a public school. She might be placed in an ESOL class with no helpful development of the essential life long skills needed to survive in society. This has been very hard for my husband and me, but we pray for the strength to endure this to the end until our daughter is able to take care of herself. I'm thankful that our current insurance company covers at half of Donna's current treatment, but it is still difficult for our family to afford."*

Donna's parents qualify for a Social Security Disability payment of \$326 per month. They have found that autism treatment in Florida is very expensive. The amount of free or reduced services available for children with autism is limited.

These are just some of Donna's monthly expenses that are not covered by the insurance company:

- Training pants and Food \$125 a month
- Speech/ Language Therapy \$180 a month (Insurance pays half)
- Behavior Analysis \$150 a month
- Occupational Therapy \$180 a month (Insurance pays half)
- Nutritionist \$225 a month
- Developmental Therapy \$120 a month

### **Noah's Story**

When families are struck by autism it is very hard to cope. Some people blame themselves, while others blame family history for a cause. It not only affects the main party, but the entire family. The family will never be the same. The hardships and sacrifices that this family has undertaken have changed them all.

Molly has two children; Noah, ten and Mickey, 14. Noah was diagnosed with Pervasive Developmental Disorder (PDD) at age six. The final diagnosis of autism was obtained after several years of looking for a concrete answer. His first symptoms were noticed at the age of 19 months; pediatricians initially treated it as an ear disorder that affected his speech and motor skills. A small procedure was performed and everything was supposed to change for the better, which never happened. It wasn't until he was taken to Miami Children's Hospital Children Psychological Evaluation Center that he was finally diagnosed correctly.

He presently receives speech, occupational, and behavioral therapy. His fathers' insurance covers an average of 30 percent of services. Noah's mother stopped working a year after the diagnosis when the extra demands for his therapies took precedence. He has been able to advance his development with this extra care. Noah has been integrated into a regular class at school with daily therapy on campus. All these accomplishments come at a cost. The marital relationship has suffered though they are very spiritual and have been able to stay together. Mickey, the older son, who is not autistic, has also had to deal with the realities of less attention. They always try to make time for him, but the demands for Noah are always more time consuming. Mickey really loves and helps his brother. Although the family does not regret the expenses, they do feel the pressure. Recently, Molly has started a photography business which will provide them with the extra cash they need to provide the therapies that Noah requires. This will hopefully give her the necessary income and the flexibility that comes with that line of work.

Molly would like to see some major changes in policy. She believes that more help should be offered for social integration. She, like many other parents, worries about the day when they are no longer there for their children. The belief is that if you help children now, they will become productive adults with very little supervision needed in the future. She also strongly believes in educating those who have early contact with the child and might be able to identify symptoms sooner. Educating the public on the matter will increase the level of tolerance for those with disabilities. If the goal is to integrate these children fully into society, education of society is essential.

Molly's hope is that lawmakers will feel compelled to assign more funds to help autistic people and families. This will benefit society as a whole.

## **Richard's Story**

Richard is a seven year old boy with autism. He was diagnosed when he was three years old at Miami Children's Hospital. He has been receiving early intervention since he was 14 months old to detect any signs of PDD. Although his diagnosis of PDD is less mild than most, he does require extensive therapy which makes the family's economic situation very difficult. His mother works for a small doctor's office that offers insurance coverage that is very expensive. Her take home pay is would be roughly \$100 a week if she opted for coverage for her family. She resorted to one of the ultimate sacrifices that many parents seeking government help have had to do. She is legally divorced from her husband so that Richard will be eligible for Medicaid; and then they had to wait for four year to coverage to be in effect. Both she and her husband had always been law abiding citizens, but with much soul-searching, they've had to abuse this loophole in the system so that Richard receives basic therapies. They tried to work within the system and did not get any help, so they had to circumvent it.

They also have a ten year old that is not autistic. This child has had trouble adapting to the complications of his brother's autism. In the beginning, he isolated himself from his brother; a dilemma for a family that has always considered itself very tightly knit. Since then, he has come to understand that his brother's difficulties must be dealt with a lot of patience.

Although the financial situation has created a hardship for the family, they are very happy with the education Richard is receiving. He has been mainstreamed into a regular public school. Currently, he attends the first grade and will graduate this coming June with very high marks. Apart form his regular teacher, he has a special education teacher that assists with his learning disabilities; and he receives extra attention from a one-on-one therapy. One of the things that he

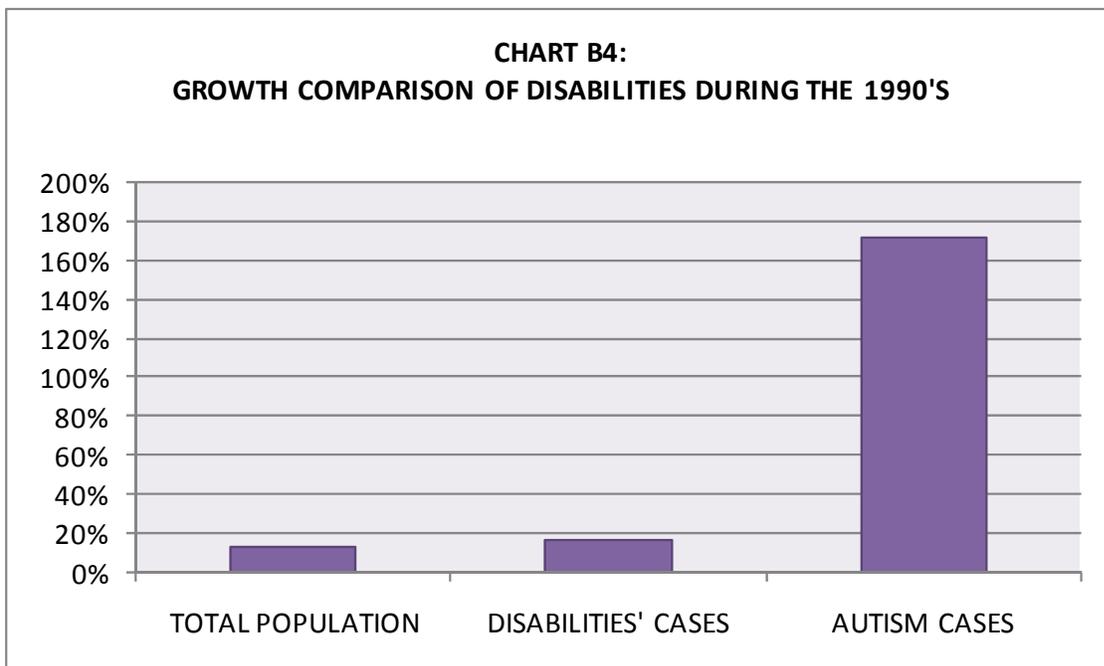
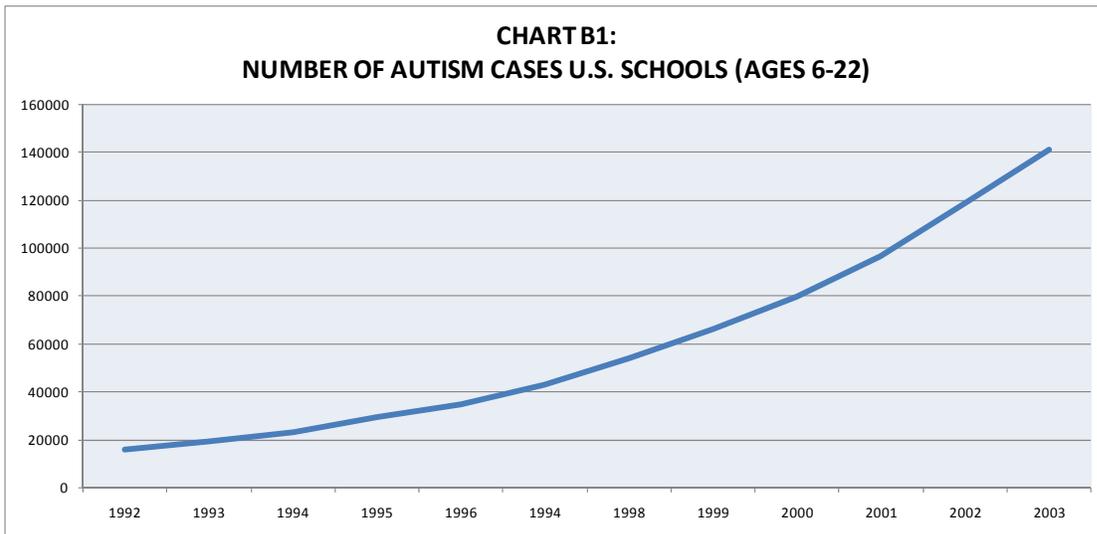
has not been able to overcome is his extreme shyness, but with socialization therapy, he will get better.

Richard receives limited speech, behavioral, and occupational therapy. Due to the lack of Medicaid funding, some of the service providers are not willing to accept it because they pay too little or do not pay quickly enough.

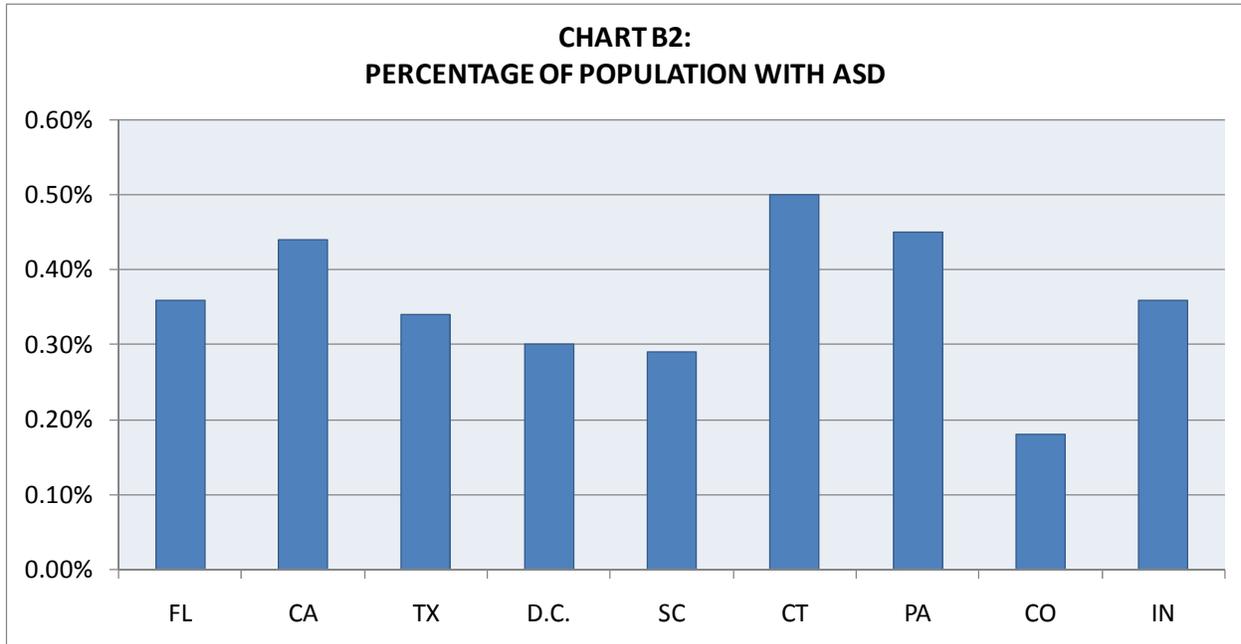
She believes that more funding should be made available to those like herself that are caught in the cracks with no other alternative than to resort to cheating the system. Also, compulsory coverage by insurance companies should be mandated through changes Florida laws.

## Emerging Epidemic

Autism has become the fastest growing disability in the last twenty years. In the U.S., one in 150 births will be autistic, and Florida is very close to the national average. Other states such as New Jersey have seen even more autistic births than any other state in the nation, but they still manage to find the resources to combat this problem.

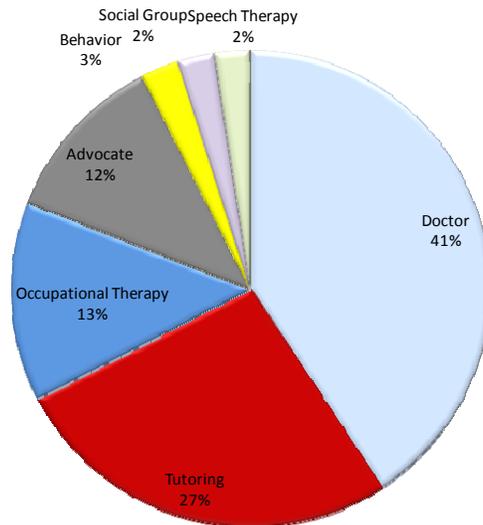


The cost of treating autism is increasing faster than inflation and other medical services; a sector of the economy that usually outpaces inflation by a large margin.



In our interviews with families, the economic impact of autism is one of the hardest factors to handle. This is just one case of a young girl who receives *most* of the services she needs:

**CHART B5:  
FAMILY CASE STUDY 2006: AUTISM OUT-OF-POCKET EXPENSES TOTALING \$12,446**



Based upon median income figures for 2004, one can see that a great portion of income is spent on taking care of autistic children. All the other members of the family must make great sacrifices in order to give the autistic child an opportunity to receive the treatment they need. As noted in all of the interviews conducted, marital relations suffer due to the added financial and emotional burdens. The national average of divorce rate for families with an autistic child is 80 percent. Although many could be attributed to those forced to seek a divorce in order for the mother to qualify for Medicaid, it is easy to see that these families are under a greater deal of strain than the typical family with healthy children.

TABLE B3:  
AUTISM GROWTH AND EXPENSES

Region <sub>1</sub>	Rate of Autistic Births <sub>2</sub>	Annual Growth Rate of Autism <sub>3</sub>	Median Household Income <sub>4</sub>	Percent of income spent on autism care <sub>5</sub>
South	0.30%	27.25%	\$42,108	62.20%
Nation	0.38%	20.00%	\$46,326	59.30%
Florida	0.36%	19.00%	\$45,446	57.70%
Midwest	0.37%	38.25%	\$46,134	56.80%
West	0.32%	32.00%	\$49,245	53.20%
Northeast	0.48%	22.00%	\$49,462	52.90%

1. Regions are comprised of states as per United States Census Bureau.
2. For the year 200X; list source(s). <http://www.oppaga.state.fl.us/reports/pdf/0340rpt.pdf>.
3. Through the years 19XX-200X; list source(s). <http://www.oppaga.state.fl.us/reports/pdf/0340rpt.pdf>.
4. Fiscal year 2005; census.gov. <http://www.census.gov/hhes/www/income/medincsizeandstate.html> (2005).
5. Percent of median household income based upon 2005 dollars; \$26,214 per person per year.

## Domestic Response

**TABLE B7:  
STATE LAW COMPARISON**

STATE	Mandatory coverage for those with autism <sup>1,5</sup>	Medical Benefits <sup>6</sup>	Education <sup>2</sup>	Age when transition services are required to be included in IEP <sup>3</sup>	Appropriated money for autism intervention and services <sup>4</sup>
INDIANA	YES	Same as physical condition limits as per HMO	YES	16, 14 if deemed necessary by IEP	\$15 M from state; \$0.0067 per \$100 of taxable property (county based)
PENNSYLVANIA	YES	\$3,000/2,000 <sup>8</sup>	YES	14	Federal: \$1,800,000 State: \$52,203,000 Total: \$54,003,000
CONNECTICUT	YES	Requires parity with physical conditions	YES	14	CT DMR <sup>6</sup> : \$3.1M
FLORIDA	NO	Does not require parity with physical conditions <sup>7</sup>	YES	16	Federal: \$3M State: \$7.5M <sup>9</sup>
NEW JERSEY	YES	Requires parity with physical conditions	YES	14	State: \$15M
CALIFORNIA	YES	Requires parity with physical conditions	YES	14	State: \$4.0B <sup>10</sup>

1. Provides health (physical, mental) and accident insurance for ASD coverage.
2. Minimal compliance with IDEA 2004.
3. Under the IDEA, transition services should begin not later than the first IEP to be in effect when the child is 16 and updated annually thereafter. The IEP must include (1) appropriate measurable post-secondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills (2) The transition services (including courses of study) need to assist the child in reaching those goals.
4. State and federal monies included; local formulas included when available.
5. Laws that specifically address insurance coverage for autism-related services or require coverage for autism-related services as part of laws that say insurers must cover autism as they do other mental/physical conditions.
6. CT Department of Mental Retardation is now the Department of Developmental Services; appropriation is for pilot program for those whose birthday is January 1, 2008 or later.
7. Florida's current mental health parity law is a mandated offering. Carriers still are allowed to restrict mental health coverage for inpatient benefits to 30 days per year; outpatient benefits for consultations may be limited to \$1,000 annually, and partial hospitalization services. Coverage beyond those limits, the staff analysis notes, does not have to equal the coverage for physical ailments and carriers are allowed to have different co-insurance and premium requirements. ([www.flains.org](http://www.flains.org))
8. Medications shall be subject to maximum benefit of \$3000 USD per month for covered individual (adjusted annually by average percentage increase/decrease of insurance premiums; Providing, in health and accident insurance, for ASD coverage: Habilitation, Psychiatric, Psychological, Rehabilitation, Respite, and Therapeutic care; 'Provide coverage for ASD to individuals less than 24 years of age: Habilitation, Psychiatric, Psychological, Rehabilitation, Respite, and Therapeutic  
Shall be subject to \$2000 USD per month for covered individual ((adjusted annually by average percentage increase/decrease of insurance premiums)' (<http://www.legis.state.pa.us>)
9. Other funding may be included in the HCBS waiver in the 2007-08 FY budget.
10. Department of Developmental Services budget for 2006-07 FY; \$2.5B from General Fund; total increase of 11percent from previous year.

As the above table indicates, Florida is falling behind other states as they quickly enact measures that will not leave the families of autistic children to fend for themselves. What follows is a brief summary of the laws found in other states concerning autism and is the basis of the law proposed for Florida.

Sixteen states have insurance laws relating to autism coverage, including ten that require coverage for autism through laws mandating coverage for mental illness. Six states have specific laws regarding insurance coverage for autism (Georgia, Indiana, Kentucky, Maryland, New York, and Tennessee). A description of the laws from those states follows.

### *Georgia*

If a policy includes benefits for neurological disorders, it is prohibited from denying benefits for autism. Such benefits are subject to the same terms and conditions as those for neurological disorders (Ga. Code Ann. § 33-24-59. 10).

### *Indiana*

Policies must include coverage for pervasive developmental disorders, including autism. Coverage may not be subject to dollar limits, deductibles, copayments, or coinsurance provisions that are less favorable to an insured than those that apply to physical illness. Insurers and HMOs cannot deny or refuse to issue coverage on, refuse to contract with, refuse to renew or reissue, or otherwise terminate or restrict coverage on an individual because of a pervasive developmental disorder diagnosis (Ind. Code §§ 27-13-7-14. 7 and 27-8-14. 2-1 through 27-8-14. 2-5).

### ***Kentucky***

Health benefit plans must include coverage, including therapeutic, respite, and rehabilitative care, for the treatment of autism for a child age 2 through 21. Coverage is subject to a maximum benefit of \$ 500 a month for each covered child (Ky. Rev. Stat. Ann. § 304.17A-143).

### ***Maryland***

Policies must include coverage for habilitative services for children under age 19. “Habilitative services” means services, including occupational, physical, and speech therapies, for the treatment of a child with a congenital or genetic birth defect, including autism, to enhance the child's ability to function. Reimbursement for habilitative services delivered through early intervention or school services are not required (Md. Code Ann. § 15-835).

### ***New York***

Policies are prohibited from excluding coverage for the diagnosis and treatment of ASD, including autism (N. Y. Ins. Law § 3221(l)(17), effective January 1, 2007).

### ***Tennessee***

If a policy includes benefits for neurological disorders, it must provide benefits for ASD to children under age 12. Such benefits must be at least as comprehensive as those provided for other neurological disorders (Tenn. Code. Ann. § 56-7-2367).

## *Connecticut*

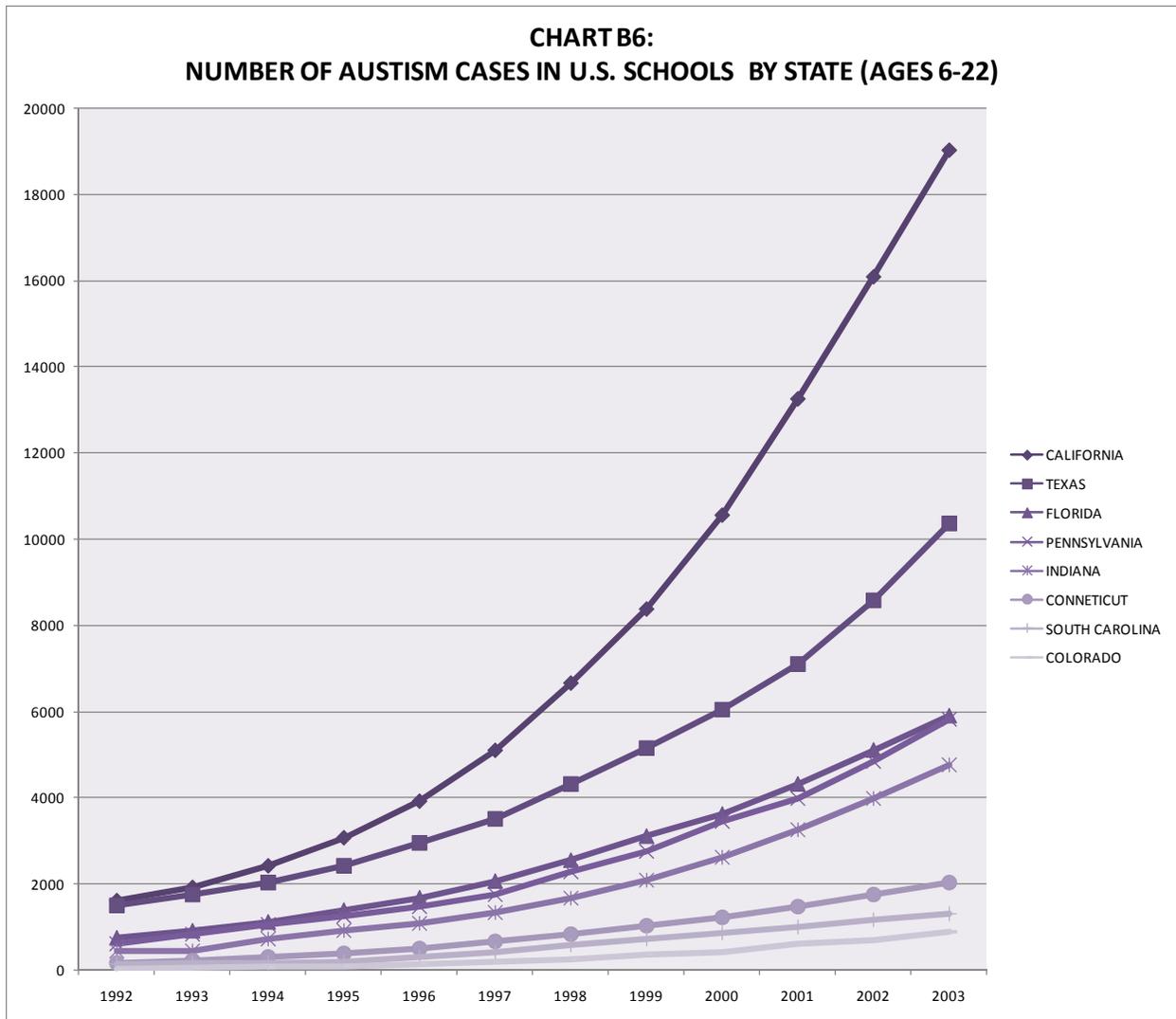
Connecticut does not have a law specifically mandating coverage of autism. Instead, its mental illness law requires health insurance policies to provide benefits for the diagnosis and treatment of mental or nervous conditions. “Mental or nervous conditions” means mental disorders, as defined in the most recent edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders”. “Mental or nervous conditions” does not include (1) mental retardation, (2) learning disorders, (3) motor skills disorders, (4) communication disorders, (5) caffeine-related disorders, (6) relational problems, and (7) additional conditions that may be a focus of clinical attention, that are not otherwise defined as mental disorders in the most recent edition of the American Psychiatric Association's “Diagnostic and Statistical Manual of Mental Disorders” (CGS §§ 38a-488a and 38a-514).

This law suggests that autism is a covered condition because DSM-IV, classifies it as a pervasive developmental disorder and distinguishes it from (1) mental retardation, (2) learning disorders, (3) motor skills disorders, (4) communication disorders, (5) caffeine-related disorders, (6) relational problems, and (7) additional conditions that may be a focus of clinical attention, that are not otherwise defined as mental disorders. It is unclear whether covered treatment includes physical, speech, and occupational therapy.

Insurance Department staff declined to comment on the extent of coverage required for autism due to their lack of medical expertise. They did note that many policies exclude custodial services, some of which are covered through the Department of Mental Retardation as part of the Birth to Three program (CGS §§ 17a-248 through 17a-248g). Policies must provide coverage for medically necessary early intervention services provided as part of an individualized family

service plan. Policies must provide (1) coverage for such services provided by qualified personnel for a child from birth until the child's third birthday, and (2) a maximum benefit of \$ 3,200 per child per year and an aggregate benefit of \$ 9,600 per child over the total three-year period (CGS §§ 38a-490a and 38a-516a).

Connecticut also mandates coverage for occupational therapy if physical therapy is covered (CGS §§ 38a-496 and 38a-524).



## International Response

**TABLE B8:  
INTERNATIONAL LAWS**

STATE	MANDATORY AUTISM COVERAGE	Medical Cost per Capita per annum <sub>6</sub>	EDUCATION <sub>2</sub>	Age when transition services are required to be included in IEP <sub>3</sub>	Appropriated money for autism intervention and services <sub>4</sub>
AUSTRALIA	YES	\$534,268	YES	NOT AVAILABLE	\$5.8 billion[1]
CANADA	YES	\$65,971	YES	16	\$2 billion
U.K.	YES	\$79178.29[2]	YES	14	\$1.98 billion[3]
SWEDEN	YES	NOT AVAILABLE	YES	16	NOT AVAILABLE
SPAIN	YES	NOT AVAILABLE	YES	14	NOT AVAILABLE

1. [http://www.aeiou.org.au/files/Exec%20summary\\_FINAL\\_May07.pdf](http://www.aeiou.org.au/files/Exec%20summary_FINAL_May07.pdf)
2. <http://www.learningdisabilities.org.uk/html/content/updatev01i17.pdf>
3. <http://www.learningdisabilities.org.uk/html/content/updatev01i17.pdf>

**TABLE B10:  
INTERNATIONAL AUTISM RATES**

COUNTRY	RATE OF AUTISM BIRTHS	ANNUAL GROWTH RATE OF AUTISM
CANADA	0.50%	0.60%
AUSTRALIA	0.63%	0.60%
U.K.	0.91%	0.80%

**TABLE B9:  
INTERNATIONAL INCOME STATISTICS**

COUNTRY	MEDIAN HOUSEHOLD INCOME	PERSONS BELOW POVERTY LEVEL
CANADA	\$43,000	15.90%
AUSTRALIA	\$35,000	12.90%
U.K.	\$39,000	17.00%

## **Autism in Australia**

One in 160 Australian children between the ages of six and 12 have an Autism Spectrum Disorder - that is over 10,000 Australian children. In New South Wales alone it is estimated that there are 9,000 children and young people with ASDs. Australian studies suggest that autism spectrum disorders are about four times more prevalent in boys than in girls.

A report released in Brisbane mark the start of Autism Awareness, gives a figure of seven billion Australian dollars (5.8 billion USD) a year. Autism experts recommend that children with the condition receive at least 20 hours of intensive therapies a week, but many are getting only an hour or two and others aren't getting any help at all. The cost to families has been estimated at \$1200 to \$3500 per month (1008 to 2939 USD) for 25 hours for various therapies.

The Constitution of Australian Advisory Board on Autism Spectrum Disorders Limited ACN 085 018 408 has a legislation that states that a company or organization can support autistic cases. The Company has been incorporated with the purpose and objective of working at a national level to alleviate the deleterious effects of autism spectrum disorders in the community at large and to enhance the support and quality of life for not only people who have an autism spectrum disorder but also their families and careers by:

- Collecting and disseminating information and fostering awareness relating to the detection and treatment of autism spectrum disorders;
- Promoting research into the causes and effective treatment of autism spectrum disorders;
- Contributing to policy development in all areas which affect the lives of people with autism spectrum disorders and their families;
- Disseminating information that contributes directly or indirectly to the support and wellbeing of people with autism and their families;

## **Autism in Canada**

In Canada, Autism is considered a developmental disorder and not a disease. As such, persons with autism are considered under current disability legislation and programs like the *Family Support for Children with Disabilities Act 2004 and the Child Welfare Act*; however, persons with autism receive some assistance for care from both the Canadian Federal government and the provincial governments. In Canada, there are federal health policies and legislation, but provinces are free to enact legislation and develop policies pertaining to health care.

## **Cost of Treating Autism in Canada**

It is very expensive to treat conditions associated with autism in Canada and the costs are not routinely covered by insurance, since the Canadian Health Act does not recognize the treatment of autism as an insured health service. According to the Hon. Terry Mercer of the Canadian parliament, the cost of treating an autistic child is between \$50,000 (46,858 USD) and \$120,000 Canadian dollars (11,2460 USD) per year depending on the severity of the condition. The treatment for Intensive Behavior Interaction (IBI), treatment based on the principle of Applied Behavior Analysis, which is teaching autistic persons through repetitive task, cost \$70,000 Canadian dollars (65,601 USD) per year. Some provinces contribute to the cost of certain treatments. For example, in British Columbia and New Brunswick, the government pays for treatment up to \$20,000 Canadian dollars (18,743 USD) per year, and this figure does not even represent 50 percent of the least amount of treatment a child needs per year. In Ontario, though support is given, it is restricted to children under the age of six. Social costs to the

treatment of autism include families having to sell their homes, going into unrecoverable debt, and financial hardship to provide therapy for their children.

According to a media release from the Ministry of Education the following are other ways that government is working with the community to support autism:

- Assessing all children referred to the Autism Intervention Program since July 2005 regardless of age
- Increasing the number of children receiving Intensive Behavioral Intervention services outside of the classroom to more than 1,100 – a 105 percent increase since April 2004
- Tripling the support for children with autism and their families since 2003-04 - increased funding to nearly \$130 million Canadian dollars (122 million USD) in 2007-08
- Increasing the number of qualified autism professionals graduating each year from the Ontario College Graduate Certificate Program in Autism and Behavioral Science to 220 by 2008-09
- Reducing the wait list for assessment by 69 per cent since 2004
- Training up to 1,600 childhood educators and child care workers and 5,000 educational assistants who work with children with autism through the Geneva Centre for Autism

The Canada Health Act does not recognize autism for insurance coverage. However, some insurance companies allow a parent to purchase a Juvenile LifeCare Rider that makes a one time payment if a child is diagnosed with certain illnesses, including autism. This is a one time payment of up to \$50,000 (46,858 USD) for a child diagnosed with autism ages 0-17.

## **Autism in Sweden**

Costs for health and medical care amount to approximately nine percent of Sweden's GDP. Seventy five percent of health care is funded through local taxation, and county councils have the right to collect tax, the average level being 11 percent. Another source of funding is contributions from the state, which represents 16 percent and 3 percent from patients' fees. The remaining 10 percent come from sales and other sources. Ten percent of health care is financed by county councils, but carried out by private health care providers.

Fees for outpatient care are decided by each county council. In order to limit costs to the individual, there is a high-cost ceiling, this means that after a patient has paid a total of SEK900 (131 USD), medical consultations in the 12 months following the date of the first consultation are free of charge. Hospital care is free of charge for children under 16. A similar ceiling exists for prescribed medication, so no one pays more than SEK 1,800 per 12 month period (262.00 USD). Generally, patients are free to choose where to go for care. Referrals may be necessary for treatment outside the region where the patient lives.

Ensuring that people with disabilities have power and influence over their everyday lives has long been the primary goal of Swedish disability policy.

## **Autism in the United Kingdom**

Statistics about the occurrence of autism are not very exact. It is estimated that more than 500,000 families throughout the United Kingdom (U.K.) have to deal with this issue. Approximately 587,900 people have autism or Asperg's Syndrome, which is equivalent to 91 per 10,000 persons of the total population of the U.K or, one in 110 people.

The economic impact of the half of million people with autism in British society is very strong, however, little is known about it. A study based on data provided by Centre for the Economics of Mental Health (CEMH) of the U.K. estimated that the lifetime cost of a person with autism exceeds £2.4 million (4.7 million USD). This implies a tremendous economical sacrifice for all of the families affected.

In U.K. education system, 12.5 percent of the special needs population has autism, and 50 percent of primary schools have at least one student diagnosed with autism.

Many programs by public and private sectors have been established. The Special Educational Needs and Disability Division (SEN) looks for every child with special education needs to reach his or her full potential in the public school system. This way an autistic child can make a successful transition to adulthood and eventually pursue higher education, training and work. However, these programs were just recently created and still need much improvement. At least 21 percent of autistic children have not been allowed to enroll in public school at least once. The discrimination against those with autism needs to be controlled with better information on the topic. The need for specially designed job opportunities for autistic adults is very important. Adults with autism have trouble finding jobs where they can be an active and productive part of society taking into consideration their disabilities. Many adults with autism say that their main goal is to find a suitable job in order to be able to support themselves.

The medical system in the U.K. is one of the most modern in the world. They are pioneers on extending health services to all citizens, and only restricting that universal coverage to the purchase of medicines. The British health system has some of the best coverage for autistic people. There is still room for improvement in order to relieve the parents of autistic

children. In addition to the health system, the British model is supported by the Social Care Services that look out for the health and welfare of the entire population of the country without restrictions. Most of the people in the U.K. are likely to become clients of Social Care Services, but some of the main groups include children or families who are in distress, people with disabilities including people with autism, people with emotional or psychological difficulties, people with financial or housing problems, and the elderly who need help with daily living activities. This entity is crucial for a family with an autistic child, and is a great way for them to get help directly from the government. The Social Care Services are offered in hospitals, schools, community groups, advice centers, or in one's home.

In addition, the U.K. has an incredible educational system very similar to the one in America. The major difference is that there is special emphasis on the education of people with disabilities.

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