

# HEALTH CARE REFORM AND THE AUTISTIC POPULATION

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by

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## **ABSTRACT**

### **HEALTHCARE REFORM AND THE AUTISTIC POPULATION**

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**SUPERVISING PROFESSOR: PHILIPPA STRELITZ**

Healthcare officials are faced with the daunting task of reforming the current healthcare system in the United States. President Barack Obama and his administration are attempting to restructure the system so that healthcare services are available to every citizen in the U.S. The new political administration brings the opportunity to make significant changes in the care and services that are provided to the special needs population. The autistic population is the focal point of this thesis. Autism spectrum disorders are

increasing and the current healthcare system does not give access to affordable services for the families. This report describes the care that is involved with an individual with autism and the struggles that families face in attempting to deliver that level of care. Additionally, the role of the family, the state, and the federal government in caring for the autistic population is described as well as current legislation that is in place and insurance issues. Barack Obama's healthcare plan is detailed with specific attention to the autistic population. A brief analysis of the plan in general and a more detailed analysis of the plan with regards to the autistic population are provided. Lastly, this thesis describes an ideal blueprint for care for a person with autism. The blueprint is intended to strike a balance between what is desirable for an advocate of autism and what is practical for a healthcare administrator.

## **INTRODUCTION**

Health officials in the United States are quick to discuss the increasing number of people who are living with chronic illnesses such as obesity, diabetes, heart disease, and HIV/AIDS. However, one subpopulation that has historically gone unnoticed but is beginning to receive more attention is the special needs population. In the context of health care reform, the United States must explore strategies to respond to a new surge in the special needs population.

Health administrators and policymakers have to develop and implement programs that give families options in caring for special needs individuals and prevent taxpayers from carrying the financial burden of this population once they reach adulthood. President Barack Obama and his administration are currently attempting to implement a health care plan that was originally described as “universal health care” and the extent to which much needed services and therapies will be available and affordable is unclear.

The new political administration presents an opportunity to make serious headway in health care reform with regards to the special needs population while restructuring health care in the U.S. Providing families with affordable resources for appropriate health care services and financial planning will help coordinate health care services and prevent many special needs adults from eventually becoming the responsibility of the state and a burden to their community.

This thesis will review existing literature that pertains to the special needs population including information about prevalence, treatments, options for financing health care services, and legislation that is in place. Additionally, the report will analyze the health care plan that President Obama has introduced and examine how the plan will address insurance coverage for treatments, research, and adult programs. Finally, this report makes several recommendations in providing access to quality health care for autistic individuals while controlling costs and will expose the barriers that Obama's health plan creates for these recommendations.

### Why Autism?

Autism is the basis for this analysis because it represents a growing and diverse group of individuals who require various therapies and service for improved quality of life. Autism spectrum disorders (ASDs) are the fastest growing and most diagnosed group of disorders in the United States. It is reported that one in 150 children have an ASD which accounts for 300,000 children across the country. With adults, the number is believed to be over a million people (CDC, 2007).

Additionally, people with ASDs represent the most familiar group in public awareness in what is considered special needs. This is largely due to the increase in celebrities and public figures that are getting involved in the autism community. Just recently, Jenny McCarthy made several public appearances to promote her book that tells of how her son was "cured" of autism and several

sport figures like Doug Flutie, Ernie Els and Kurt Warner have been open about autism in their families.

Furthermore, the “autism boom” is quickly approaching as the current autistic population ages and more and more babies are diagnosed with a disorder on the spectrum. The U.S. is grossly under prepared to deal with the autistic population, as well as those with other developmental disorders and disabilities, as they reach adulthood and may be facing yet another health care crisis.

### Key Considerations

Three areas of the Obama health plan merit closer inspection. The first major issue falls under the category of insurance coverage for treatment of autistic individuals. In describing his health care plan, Obama simply stated that all Americans would have access to health services but which services and how much were not disclosed. Will some of the therapies that are seemingly necessary for autistic individuals be included in the Obama plan? An analysis of the plan and of universal health care in general will be necessary to determine if autistic individuals will have access to essential therapies or treatments under his administration.

Another pressing issue is whether research funding will be affected by the implementation of Obama’s health plan. He has been openly supportive of research and has promised to designate funds for autism (Obama, 2009c). The important question here is whether Americans will be willing to shoulder the tax burden. Already critics of the plan are concerned about the additional taxes that

may be placed on families to fund the health plan. Research is a field where results are not immediately seen, so often there is question as to the importance of continuing when the money could be reallocated to other areas. A close analysis of current and impending legislation regarding research will help understand where crucial research dollars are being spent and if there is enough funding given to ASDs.

Finally, there is the question of what is to be done about the autistic adults. Currently, state programs terminate services to autistic individuals once they reach the age of 22 (Autism Speaks, 2007a). At that point, families are at a loss as to where they can go for continued services and how they are going to pay for them. Although there has been no mention of development or implementation of new adult programs in the Obama health care plan, further research is necessary to interpret his intentions with this population. A gap analysis is necessary to determine what the country offers for residential homes and programs for autistic adults and what the demand will be in the future with the influx of developmentally delayed individuals reaching adulthood. Additionally, the researcher will outline a method for health care administrators to meet the needs of the aging autistic population and their families.

To address these questions, it is crucial that there is a comprehensive understanding of what the symptoms and struggles are for a person considered special needs. Chapter one will give a detailed overview of a few of the syndromes that are increasing in prevalence and some predictions for the special

needs population in the United States. The chapter will also describe some of the treatments that are necessary for autistic individuals.

Chapter two describes the current health care system in general and then gives an idea of challenges that autistic individuals and their families face in attempting to finance health care services. Additionally, this chapter explores the extent to which the state is contributing to the provision of services and what legislation is in place to aid in the provision of necessary services on a federal level.

Chapter three gives an overview of Barack Obama's health care plan and his intentions for helping the autistic population. It outlines what he has stated in his plan for the improvement of insurance coverage, autism related research and necessary steps for helping adults with autism.

Chapter four provides the basis for this paper. The chapter analyzes Obama's health care plan and the promises that he has made regarding the autistic population. It delves into the legislative history of Obama regarding autism and special needs and makes predictions for the effect that his health care reform will have on the autistic population.

The final chapter in this report provides a blueprint for meeting the needs of the autistic population. It outlines what can be done on a federal, state and local level to deal with the surge of autistic adults. Additionally, the chapter outlines steps that managed care can do to prepare for the impending "autism boom" and improve cost, quality, and access to these individuals and their families.

## **CHAPTER I**

### **THE SPECIAL NEEDS POPULATIONS**

People with ASDs are not the only special needs group with extraordinary health care requirements. The disorders and conditions included under the umbrella of “special needs” affect people of all ages and ethnicities. People who are labeled special needs can have Down’s syndrome, cerebral palsy (CP), autism and other forms of mental retardation, among other conditions (HHS, 2002). The level of impairment with each syndrome varies from person to person and cannot be predicted. The treatments for children and adults living with these disorders are expensive and many times not covered by insurance (Autism Speaks, 2007a). This topic will be discussed in greater detail later in this study.

To better comprehend the financial impact that living with a disorder can have on an individual, a family, the state and the country as a whole, it is important to have some background information on some of the disorders. For the purposes of this report, “special needs” includes those populations with Down’s syndrome, CP, mental retardation and ASDs with the most emphasis on those with autism. These disorders identified as a focus have been chosen because of their relative familiarity to the general public.

### Down's syndrome

Down's syndrome is present in 1 in 800 births. The chances for having a child with Down's syndrome increase as a woman gets older. For instance, a woman over the age of 40 has a 1 in 60 chance of giving birth to a baby with Down's syndrome, while at 49, the chances increase to 1 in 49 (CDC, 2004a).

People with Down's syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down's syndrome lead healthy lives. Currently, there are approximately 400,000 people in the United States that have Down's syndrome (NDSS, 2008).

In the past, people with Down's syndrome did not live past their twenties but with advances in technology and medicine, the life expectancy has increased to 60 years or more (CDC, 2006). As a person with Down's syndrome ages, changes in body structure and a decline in function due to aging greatly limit what they can do without assistance (Barnhart and Connolly, 2007).

### Cerebral Palsy

Approximately 10,000 infants and babies are diagnosed with CP each year and between 1,200 and 1,500 children are diagnosed at preschool age (CDC, 2004b). Approximately one million people in the United States have CP. Improvements in prenatal, pediatric, and intensive care over the past 30 years have enabled more critically premature and frail babies to survive infancy. Many of these surviving children suffer developmental disorders and neurological

damage (Neurology Channel, 2008). Currently, the life expectancy of someone affected with CP is that of a person with no abnormal health condition (CDC, 2004b).

### Mental Retardation

An umbrella term used to describe any individual with an IQ under 80 is “mentally retarded” or MR. This condition is considered an intellectual disability and is typically used to label children and adults who have not been diagnosed with any condition yet are not developing typically. According to the Center for Disease Control, there are 1.5 million children and adults in the United States who are considered MR. People with mental retardation have a normal life expectancy as well (CDC, 2005).

### Autism Spectrum Disorders

ASDs include classic autism, Asperger syndrome, Rett syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (PDD-NOS) (NINDS, 2006). ASDs are five times more common than Down’s syndrome, affecting between three and six people in a 1,000 (CDC, 2007). The National Institute of Health wrote in 2007 that there was no sure way of determining the prevalence of ASD but according to the Center for Disease Control there are approximately one million people in the U.S with some form of autism (2007).

The most recent statistic says that one in 150 children have an ASD (CDC, 2007). Using this statistic and the reported 4 million births in the U.S. each year (Census Bureau, 2008), it can be estimated that there are

approximately 27,000 new cases of autism each year. Another way to look at it is that each year there are 27,000 more autistic people that are going to reach adulthood and need medical services that are most likely not going to be covered under insurance plans.

The causes of ASD have been and remain up for debate. ASD has been attributed to, among other things, mercury used to preserve vaccines, environmental issues, genetic disorders, and in much earlier times, cold and unaffectionate mothers (NINDS, 2006).

The only known cause of autism is fragile X syndrome. Fragile X syndrome is less known, but significant, because it is a genetic disorder carried by 1 in 250 women and 1 in 800 men, most unknowing. One third of people that have fragile X syndrome are autistic and yet very few people know about fragile X syndrome, including health care providers. The current statistic of one in 150 may prove to be conservative if there are more genetic conditions that are discovered to contribute to autism. People with fragile X syndrome also have a normal life expectancy (FRAXA, 2007).

#### Total Number of People Considered Special Needs

Given the information outlined above, it can be approximated that there are four million people in the United States that are considered special needs. This is according to the definition provided in this paper. Whatever the cause, more and more people are in need of health care services that are not readily available in the current health care system. Unbelievably, the number of people

over the age of 60 with lifelong developmental delays is predicted to double by 2030 (Barnhart et al., 2007).

### Improving Quality of Life

With ASDs, an enormous amount of treatment and therapy is necessary for individuals. Therapy is recommended starting as early as age two and lasting throughout their lives. Physical therapy (PT), occupational therapy (OT), behavioral therapy and speech therapy are commonly accepted forms of treatment for these individuals. Equestrian therapy, music therapy and vision therapy are also helpful in treatment (Rudy, 2009).

Other equipment that is necessary in treatment can include wheelchairs, orthotic devices and walkers. There is usually medication taken on a daily basis and some may need communication aids such as computers with attached voice synthesizers (NINDS, 2006). Below is a description of the more popular therapies and how they can be used to help an autistic patient.

### Occupational Therapy

OT is defined by the American Occupational Therapy Association executive board (1976) as: "The therapeutic use of work, self-care, and play activities to increase development and prevent disability. It may include adaptation of task or environment to achieve maximum independence and to enhance the quality of life." OT is a health care profession aimed at improving performance, preventing illness and disability, and promoting adaptation to life challenges or changes. In this field, occupational therapists help people,

including those with disabilities, live healthier, happier, and more productive lives (Rudy, 2007a).

In the case of autism, occupational therapists have been forced to expand the breadth of their job. Typically, OT is used to help individuals with activities of daily living (ADL) such as feeding, dressing, grooming or work related activities. More specifically things like improving handwriting, buttoning a shirt, zipping a jacket, or tying a shoe may be goals for autistic individuals (Rudy, 2007a).

To better help autistic individuals, occupational therapists also have to be well schooled in sensory integration (SI). Individuals that have problems with sensory integration have “difficulty processing information through the senses.” For autistic individuals, struggling with sensory integration can cause over-stimulation and result in undesirable behaviors. Sometimes, the behaviors are violent to the individual or those around them (Rudy, 2007a).

Since people with autism often lack some of the basic social and personal skills required for independent living, occupational therapists have developed techniques to help each individual work on all of these needs. These activities are oftentimes taught to the caregiver as well as the individual in order to reinforce the therapeutic effect. The following are examples of what an OT may do in therapy for an autistic individual:

1. Provide interventions to help a child appropriately respond to information coming through the senses. Intervention may include swinging, brushing, playing in a ball pit and a whole gamut of other activities aimed at helping a child better manage his body in space.

2. Facilitate play activities that instruct as well as aid a child in interacting and communicating with others. For the OT specializing in autism, this can translate specifically into structured play therapies, such as floor-time, which were developed to build intellectual, emotional, and physical skills.
3. Devise strategies to help the individual transition from one setting to another, from one person to another, and from one life phase to another. For a child with autism, this may involve soothing strategies for managing transition from home to school; for adults with autism it may involve vocational skills, cooking skills and more.
4. Develop adaptive techniques and strategies to get around apparent disabilities (Rudy, 2007a).

### Physical Therapy

Autism is a pervasive developmental disorder (PDD). This means that most people on the autism spectrum have delays, differences or disorders in many areas, including gross and fine motor skills. Children on the spectrum may have low muscle tone, or have a tough time with coordination and sports. These issues can interfere with basic day-to-day functioning and they are almost certain to interfere with social and physical development (Rudy, 2007b).

Children with autism would rarely be termed physically disabled; however, most do have physical limitations. There are some autistic children with very low muscle tone which may make it difficult for them to sit or walk for long periods (Rudy, 2007b).

Physical therapists may work with very young children on basic motor skills such as sitting, rolling, standing and playing. They may also work with parents to teach them some techniques for helping their child build muscle strength, coordination and skills (Rudy, 2007b).

As children grow older, physical therapists are more likely to come to a child's preschool or school. There, they may work on more sophisticated skills such as skipping, kicking, throwing, and catching. These skills are not only important for physical development, but also for social engagement in sports, recess and general play (Rudy, 2007b).

In school settings, physical therapists may pull children out to work with them one-on-one, or attempt "inclusion" to typical school settings such as gym class to support children in real-life situations. It is not unusual for a physical therapist to create groups including typical and autistic children to work on the social aspects of physical skills. Physical therapists may also work with special education teachers and aides, gym teachers, and parents to provide tools for building social/physical skills (Rudy, 2007b).

### Speech Therapy

Almost anyone diagnosed with an autism spectrum disorder will require speech therapy. This may seem odd, as many autistic people at the lower end of the spectrum are either non-verbal or those at the upper end of the spectrum are extremely verbal. But even very verbal autistics are likely to misuse and misunderstand language on a regular basis. And even non-verbal people can

certainly develop communication skills and may even develop spoken language skills over time (Rudy, 2008b).

Speech therapy involves much more than simply teaching a child to correctly pronounce words. In fact, a speech therapist working with an autistic individual may work on a wide range of skills including:

1. Non-verbal communication. This may include teaching gestured communication, or training with picture exchange cards (PECS), electronic talking devices, and other non-verbal communication tools.
2. Speech pragmatics. This helps the person know when, how and to whom you should use the language that he or she has developed.
3. Conversation skills. Many autistic people know how to make statements but this is not the same thing as carrying on conversations. Typically, they will repeat what they heard and may or may not offer a response. Speech therapists may work on back-and-forth exchange.
4. Concept skills. A person's ability to state abstract concepts does not always reflect their ability to understand them. Speech therapists may work on building such concepts (Rudy, 2008b).

### Applied Behavior Analysis

Applied Behavior Analysis (ABA) attempts to understand, to explain, to describe and to predict the behaviors of people and animals with regards to the environment. It is used in many types of situations ranging from education to

industry. Successful programs grounded in behavior analysis are well documented in clinical areas related to personal problems, parenting, child-rearing, corrections, drug and alcohol treatment, and in health-related areas, such as weight control and smoking cessation (Saffran, 2007).

With regards to treatment in autism, ABA is essential. Starting in the 1960s, researchers began to document the importance of ABA in the treatment of autistic individuals. These days, most, if not all, individuals with autism have been exposed to some form of ABA. ABA programs for autistic individuals often combine many research-validated methods into a comprehensive but individualized package (Saffran, 2007).

### Medications

In addition to therapeutic approaches, many autistic people are on various medications. Medications do not cure autism, but are meant to control symptoms. Antidepressants, anti-anxiety, psychotropic medications, and stimulants that help regulate mood and behavior are included in the medications that an autistic person may take to manage symptoms (Dombeck & Reynolds, 2006).

The antidepressants and anti-anxiety drugs are used to help control self-stimulatory behavior, repetitive movements and outbursts or tantrums. Psychotropic medications are used to reduce aggression and repetitive movements as well as aid with social withdrawal. Stimulant medications are used for improving concentration and for reducing hyperactivity and impulsiveness (Dombeck et al., 2006).

### Summary

This chapter outlined some of the different disorders that are included in the special needs population. While there are many illnesses and syndromes that greatly impact the lives of individuals and their families, the main focus of this report will be on autism spectrum disorders. This chapter described the multi-faceted care that is required for autistic individuals to reach their fullest potential. The next chapter brings attention to the flailing health care system and the struggles that an autistic person may encounter in trying to obtain essential health care services.

## **CHAPTER II**

### **AUTISM AND THE CURRENT HEALTH CARE SYSTEM**

There are considerable challenges in the U.S. health care system. Forty-six million people are believed to be uninsured or underinsured (Census Bureau, 2008). Out of pocket expenses continue to increase for patients, while employers are finding it more and more difficult to afford insurance for employees. Additionally, there are fewer students in medical school and the need for more practitioners is intensifying due to the aging population (HCA, 2009).

Baby boomers are beginning to hit retirement age and the Medicare system may not be equipped to handle the vast number of people in need of coverage (Collins, Davis, Doty, Kriss & Schoen, 2006). The World Health Organization (WHO) ranked the current health care system 37<sup>th</sup> in the world for quality or fairness and the U.S. is the only industrialized country that does not offer universal health coverage (HCA, 2009).

The Rand Corporation recently reported its findings that 60 percent of the care in the U.S. is substandard. The findings included some of the most prestigious hospitals in the country. It found that while the costs of health care

had continued to increase, the quality of care declined in almost equal proportion (HCA, 2009).

In California, for example, there are over 1500 insurance plans, yet seven million Californians are uninsured and millions more are underinsured. Costs are rising for premiums, copays and deductibles but overall there is less coverage. In most cases, a major portion of the health care expenditures goes towards administrative costs, large executive commissions, and stockholder dividends while very little actually is allocated for health care services. The study also reported that half of personal bankruptcies are caused by medical bills and the lack of medical insurance is the seventh leading cause of death in the United States (HCA, 2009).

These statistics prove that the health care system is in need of reform. For families of those that have autism, maneuvering through the system may be even more difficult. There are increasing numbers of “pre-existing conditions” that the insurance companies are excluding from coverage. Unfortunately, autism can fall under that category.

#### Health Care Services for the Autistic Population

With ASDs, there are so many different ways that an individual can be affected. Treatment is usually a case of trial and error. Whether or not OT, PT, Speech, and ABA are covered by insurance varies from state to state. Most states have statutes that include the diagnosis and treatment of autism but the therapies and services that are included in that coverage are unclear. Sixteen

states have laws that require coverage for treatments related to autism, while only six states have implemented laws specifically for ASDs (Kaminski, 2006).

The states that address ASDs specifically are Georgia, Indiana, Kentucky, Maryland, New York and Tennessee. Some of these six states are somewhat vague in what is actually covered. This leaves room for interpretation and can result in lengthy negotiations between the insurance companies and the families. For instance, New York State Law simply says, "Policies are prohibited from excluding coverage from the diagnosis and treatment of ASD, including autism, effective January 1, 2007 (Kaminski, 2006).

Kentucky has an equally indistinct law stating, "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 (Kaminski, 2006)."

The only state that mentions the therapies specifically is Maryland. It states that:

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 (Kaminski, 2006).

Historically, ABA is almost never covered by insurance companies. It is too expensive and some companies believe the results are too slight and questionable overall (Autism Speaks, 2007a). There are some states that are passing laws requiring insurance companies to provide ABA up to a designated annual amount. For example, in 2008, Louisiana Governor Bobby Jindal signed

into law HB 958, which makes Louisiana one of eight states, to date, that have taken necessary steps to help children with autism get the help they need. The law requires insurers to cover up to \$36,000 a year for ABA and other necessary treatments until age 17. While \$36,000 does not cover all of the expenses of ABA, it does offset some of the costs that can be up to \$100,000 annually (Autism Speaks, 2008).

### The Burden of Care for the Family

The financial burden of raising a child with an ASD can be staggering. A U.S. study estimated that the average additional lifetime cost due exclusively to autism to be \$3.2 million for an individual born with autism in the year 2000; 10 percent is for medical care, 30 percent is for non-medical care, and 60 percent is the lost of economic productivity of individuals and their parents (Myers & Johnson, 2007).

At school age, parents are faced with a difficult decision regarding the education of their autistic child. A growing number of families are choosing to educate their children in private schools, believing public schools could not deal with the sometimes aggressive and unpredictable behavior of an autistic child. There is also an increasing distrust in the public schools in general where special education classrooms are thought of as more of daycare than a classroom (Abramson, 2007).

Private placement is very expensive. For example, the May Institute, located outside of Boston, receives an average of \$75,000 per year for day students (Abramson, 2007). Schools like the May Institute include physical,

occupational and speech therapies in the daily activities of the student so it may seem as if the school is a bargain for some families. However, the \$75,000 price tag does not include transportation to and from school; which is a serious concern given that autism specific schools are not exactly in every neighborhood. Furthermore, the costs to send a child to a private school are completely out of pocket for the families and there is very little government subsidies given to these families (Douglas & Martin, 2007).

Then there is the autistic adult. Texas is a great example of a state system that leaves families with few options in caring for their autistic family member once he or she passes school age. In Texas, there are health care services provided by the state through the public school system until the person is 22 years old (Texas Department of State Health Services, 2007). At that point, the parents have to go to court to become legal custodians of the individual or they become wards of the state. After the age of 21, the state no longer covers educational or therapeutic services (Texas Department of State Health Services, 2007). This information begs the question: Where do these individuals go after they turn 22? The options are limited and the costs will ultimately determine whether an autistic adult will live with their parents or another family member, in a group home, assisted living residencies, nursing homes or in state hospitals (NIMH, 2009).

Not only are the costs of caring for a person with special needs astounding but there seems to be a variance in the out-of-pocket costs that are incurred by families. A study conducted by Washington State University in St.

Louis shows that the extra costs that families face in providing care for these individuals depends on the state in which the family lives. The group studied faced an average extra out-of-pocket cost of \$774 per year. The study also discovered that there was a correlation between the overall wealth of the state and the amount of out-of-pocket expenses occurred by these families. Families in the poorer states, predominantly in the south, shouldered higher costs compared to those in wealthier states like Massachusetts (Martin, 2008).

This study showed that the average percent of families that are paying extra out-of-pocket costs ranged from 86.11 percent to 94.24 percent with the poorer states showing at the high end of the ranking. Obviously, programs like Medicaid are not doing enough to help families with children who have special needs. There needs to be a method for providing for the families that have less income but are feeling more of the financial burden when caring for their family members (Martin, 2008).

#### The State's Role in Providing for Autistic People

The majority of the costs that are incurred by the states for providing services for autistic individuals are through the public education system. From the age of 3, autistic children are allowed to enter public schools. It is estimated that a child that has been diagnosed with autism costs a school district \$50,000 annually. Some of the costs are for the additional services like physical, occupational, and speech therapy, and for the labor costs involved in providing enough staff for the special education children. All school districts have regulations for student to teacher ratio and the ratio is higher for special

education classrooms. Many of the schools also have to outsource for therapists which drives the cost of providing these therapies up tremendously (Choi, 2004).

According to the CDC, the number of children in special education programs increased from 22,664 to 211,610 from 1994 to 2006. There are several different ways that the education for each of these children is funded. Federal funds average \$1,461 per child annually and the remaining funds are provided by the state. There is typically a lump sum given annually to the school plus there is a designated amount per child; usually around \$2,500 to \$3,000 per child (Calvani, 2009).

In addition to educational services, some states are using Medicaid funding to provide care for autistic individuals. The majority of the states are providing some services to autistic individuals, although the requirements for eligibility and the extent of coverage vary.

Forty-four states and the District of Columbia have received waivers to provide what are referred to as home-and-community-based services (HCBS) to people with developmental disabilities. The issue here is that the definition of developmental disability may not include autism in every state. There are four states that have received autism-specific waivers. They are Colorado, Indiana, Maryland, and Wisconsin (Spigel, 2007).

General Medicaid waivers for HCBS allow for individuals who would otherwise need long-term institutional care to receive service in their communities. Each state has eligibility requirements and enrollment limits as well as the right to determine the services that are covered under the waiver.

Financial eligibility requirements mean that the person must be Medicaid eligible. There is also an eligibility requirement related to diagnosis. Because the individual must require long-term institutionalized care, this typically excludes higher functioning individuals like those with Asperger syndrome or PDD-NOS. Additionally, there are always age requirements and if the state has a long waiting list, which is almost the case, then some of the individuals miss the window of eligibility. This is particularly detrimental to children since early intervention has been crucial in the treatment of autistic individuals (Spigel, 2007).

Colorado, Indiana, Maryland and Wisconsin have autism-specific Medicaid waivers. The primary difference between the general waivers and the autism-specific waivers is that the autism waivers target early intervention. The waivers are all specific to those under the age of 22, while Colorado only provides services until the age of 6 (see Appendix A). Colorado caps the services at \$25,000 a year but the other states do not, they choose instead to cap the enrollment. In either case, there is the potential for great expenses incurred to care for only a small percentage of the autistic population (Spigel, 2007).

There are only three states that have a distinct unit that is responsible for overseeing or providing services for autism. They are Massachusetts, Pennsylvania, and South Carolina. Sadly, there are five states-Alabama, Connecticut, Massachusetts, Mississippi, and Virginia-that excludes autism unless the person can also be considered mentally retarded (Spigel, 2007).

### Federal Legislation Regarding Services for the Autistic Population

When it comes to the autistic population, the federal government seems a little apprehensive about expanding coverage for necessary health care services. However, the federal government has implemented some laws that are helping autistic individuals when it comes to education. Luckily, legislation requires the school system to provide services such as PT, OT and speech in order to give the individual an opportunity to get an appropriate education. Below are some examples of legislation where health care and education collide.

#### Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) Part B is a federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities from age 3 until the age of 21. Part C of the IDEA requires that infants and toddlers with disabilities receive early intervention services from birth through age 2 (Logsdon, 2009).

States are not required to participate but there are financial incentives for states that choose to adopt at least the minimum policies and procedures specified in IDEA. Every state has chosen to participate (Logsdon, 2009).

IDEA seeks to provide every disabled person with a Free and Appropriate Public Education (FAPE) that prepares them for further education, employment and independent living. Under IDEA, public schools must provide an Individualized Education Program (IEP) for each student eligible under the state and federal standards. The IEP specifies the services to be provided and how

often, describes the student's present levels of performance, how the student's disabilities affect academic performance, and specify accommodations and modifications to be provided for the student. IDEA also describes the theory of "least restrictive environment." Simply put, the least restrictive environment is that which is most like that of a typical child in which a child with a disability can succeed academically as measured by the specific goals in the student's IEP (Logsdon, 2009).

Under the related services clause, schools are specifically required to pay for many kinds of medical treatments, including speech therapy, audiology, PT and nursing if the medical treatment is expected to help with the student's education (Logsdon, 2009). There is no inclusion for ABA.

#### No Child Left Behind

The No Child Left Behind Act of 2001 (NCLB) is a complex, sweeping, controversial law that was passed as a reaction to the low academic achievement exhibited by so many public school students in the United States. The fundamental aspect of the law is to hold states, school districts, principals, and teachers accountable for making meaningful improvements in students' academic performance. This pertains to general and special education (Drasgow, Lowrey & Yell, 2005).

Under NCLB, students with disabilities are to be held to the standards for the grade in which the student is enrolled, although accommodations, modifications, or alternative assessments may be needed depending on the severity of the disability. To receive these services, the student must be eligible

for special education service under IDEA or section 504 of the Rehabilitation Act of 1973 (Drasgow et al., 2005).

One of the major criticisms of NCLB with regards to children with autism is that in order to truly assess that abilities of the child, there are certain measures that need to be taken to aid the student in the process. Such measures are almost always aligned with the implementation of ABA. NCLB, like IDEA, does not provide for, or even address, the need for ABA therapy and therefore is in conflict with its goal of providing an appropriate education services to this population (Drasgow et al., 2005).

#### Combating Autism Act

The Combating Autism Act (CAA) was designed to enhance research, surveillance, and education regarding autism spectrum disorder. The Act authorizes research under the National Institute of Health to address the entire scope of ASD (Autism Speaks, 2006).

The Act also developed Regional Centers of Excellence for Autism Spectrum Disorder Research and Epidemiology. These Centers collect and analyze information on the number, incidence, correlates, and causes of ASD and other developmental disabilities. The Act also provides grants to states for collection, analysis, and dissemination of data related to autism (Autism Speaks, 2006).

The Act supports activities to increase public awareness of autism, improve the ability of health care providers to use evidence-based interventions,

and increase early screening for autism. Additionally, the act sanctions the Secretary of Health and Human Services to:

1. Provide information and education on ASD and other developmental disabilities to increase public awareness of developmental milestones.
2. Promote research into the development and validation of reliable screening tools for ASD and other developmental disabilities and disseminate information regarding those screening tools.
3. Promote early screening of individuals at higher risk for ASD and other developmental disabilities as early as practicable.
4. Increase the number of individuals who are able to confirm or rule out a diagnosis of ASD and other developmental disabilities.
5. Increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with ASD or other developmental disabilities.
6. Promote the use of evidence-based interventions for individuals at higher risk for ASD and other developmental disabilities as early as practicable” (Autism Speaks, 2006).

The Act calls on the Interagency Autism Coordinating Committee (IACC) to enhance information sharing. The IACC provides a forum to facilitate the efficient and effective exchange of information about autism activities, programs, policies, and research among the federal government, several non-profit groups, and the public. The Combating Autism Act requires the IACC to provide information and recommendations on ASD-related programs and to continue its

work to develop and update annually a strategic plan for ASD research (Autism Speaks, 2006).

The CAA authorized \$640 million over five years to expand and to intensify autism basic and clinical research conducted by NIH to investigate the causes, including possible environmental causes, early detection, prevention, health care and support services, intervention, and treatment of autism spectrum disorder (Autism Speaks, 2006).

Congress directed the IACC to develop, submit, and annually update a comprehensive Strategic Plan (SP) with a budget for the conduct of this research. However, the appropriations to carry out this plan must be passed by Congress each year, especially reserved for autism, so that the research set forth in the plan does not get ignored amidst the vying for the \$28 billion or so allocated generally to the NIH (Autism Speaks, 2006).

#### S.937-Expanding the Promise of Individuals with Autism Act

Autism Speaks, the nation's leading autism advocacy organization joined with then Senator Hillary Rodham Clinton (D-NY) and Senator Wayne Allard (R-CO), in the introduction of the Expanding the Promise for Individuals with Autism Act of 2007 (EPIAA). This Act was considered landmark legislation that would dramatically expand federal funding for life-long services for people with autism. The EPIAA would authorize approximately \$350 million in new federal funding, above and beyond all existing federal dollars, for key programs related to treatments, interventions and services for both children and adults with autism (Autism Speaks, 2007b).

Among the EPIAA's key elements is the authorization of a task force that will include significant representation from the autism community and will report to Congress and the Executive Branch on the state of evidence-based biomedical and behavioral treatments and services for both children and adults with autism, including identifying gaps in applied research on such treatments, interventions and services. It would also mandate a GAO study on service provision and financing (Autism Speaks, 2007b). EPIAA would also authorize a variety of grants:

1. \$20 million in annual demonstration grants for the coverage of treatments, interventions and services;
2. \$20 million in annual planning and demonstration grants for services for adults with autism;
3. \$10 million in grants in FY09 (growing to \$20 million by FY12) for the expansion of access to immediate post-diagnosis care;
4. \$13.4 million annually in training grants for the University Centers of Excellence for Developmental Disabilities for training, technical assistance and additional services for individuals with autism and their families; and
5. \$6 million in annual grants for protection and advocacy systems to better meet the needs of families facing autism and other developmental disabilities, including legal representation (Autism Speaks, 2007b).

The real significance of this legislation is that for the first time, legislators are addressing the needs of autistic adults and not just children. It marks the beginning of the realization that the autistic population is not only growing rapidly, but aging in a country unprepared to meet their health care needs. Jon Shestack, Autism Speaks board member and co-founder of Cure Autism Now (CAN) said of the legislation, "This is an important and compassionate piece of legislation for many reasons, but perhaps most of all because it remembers those who are most frequently forgotten and that is the adults, be they 22 or 72, who are struggling daily with the challenges of autism. The EPIAA will make dramatic and real change in the lives of thousands of Americans with autism and their families" (Autism Speaks, 2008).

#### Developmental Disabilities Assistance and Bill of Rights Act

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) ensures that individuals with developmental disabilities participate fully in their communities through full integration and inclusion in the economic, political, social, cultural, religious and educational sectors of our society. The DD Act further ensures that individuals with developmental disabilities and their families participate in the design of, and have access to, culturally competent services, supports and other assistance and opportunities that promote independence, productivity, integration and inclusion in the community (Work World, 2009).

The Developmental Disabilities Act requires the Administration on Developmental Disabilities to ensure that people with developmental

disabilities and their families receive the services and supports they need and participate in the planning and designing of those services. The DD Act established eight areas of emphasis for ADD programs: employment, education, child care, health, housing, transportation, recreation, and quality assurance (Work World, 2009).

ADD meets the requirements of the DD Act through the work of the programs described below. These programs work individually and collectively to ensure a strong foundation for DD services and supports necessary for the inclusion of children and adults with developmental disabilities in all facets of community life (Work World, 2009).

#### Rehabilitation Act

The Rehabilitation Act is the Federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, and client assistance. It also authorizes a variety of training and service discretionary grants administered by the Rehabilitation Services Administration. The Act authorizes research activities that are administered by the National Institute on Disability and Rehabilitation Research and the work of the National Council on Disability. The Act also includes a variety of provisions focused on rights, advocacy and protections for individuals with disabilities (U.S. Department of Education, 2004).

#### Research towards a Cure

Before 2006, NIH funding for research for autism was \$100 million. In December 2006, the Combating Autism Act was signed by President Bush. The

bill authorized nearly \$1 billion in autism-related funding over the span of 5 years. This was supposed to increase federal spending for autism research by 50 percent. The funding was to begin in 2007 and has specific goals such as strategic planning, budget transparency, Congressional oversight, and more involvement for parents of children with autism in the federal decision-making process (Autism Speaks, 2006). The total NIH budget for 2007 was \$29 billion. Of that amount, approximately \$80 was used for autism research, representing only 0.28 percent of the total budget (Autism Speaks, 2009).

When looking at the incidence of certain diseases compared to the private funding that research for these diseases receives, it is apparent that autism receives far less than those diseases that are not as prevalent. For instance, Leukemia affects 1 in 25,000 and receives \$310 million, pediatric AIDS affects 1 in 8,000 and receives \$394 million and muscular dystrophy affects 1 in 20,000 and receives \$175 million in research funding. Autism affects 1 in 150 and receives only \$42 million annually for research (Autism Speaks, 2009).

#### Adult Programs for Autistic Individuals

It is difficult to determine how many adults are living with ASD today. This is because there have been changes made to the criteria and methods of diagnosis in recent years. Some would argue that the label of autism is used as a “catch all” for diagnosing unexplainable developmental delays or behaviors. Because there is no prevalence data pertaining to adults, it is difficult to know where the system is weak in caring for this population and what plans need to be made in order to better provide for generations to come.

What is known is that there are a large number of children that are coming in to adulthood that have been diagnosed with ASD and that probably the toughest of challenges for families is planning for the future of the child. Long term care is almost always necessary for a special needs adult. While the families may not want the autistic individual to leave home immediately after turning 22, realistically at some point, living arrangements outside of the home will have to be made.

There are some choices in living arrangements once the individual reaches adulthood. For those that are higher functioning, independent living is an option. Even if the individual requires some assistance in making major decisions, arrangements can be made for a family member, state agent or another provider to help while allowing the individual to remain as autonomous as possible (National Institute for Mental Health, 2009).

The current trend is for these individuals to remain in the home of their parents. There are two major contributing factors to this trend: societal pressure and distrust in institutions. There are some government funds available for families that make this choice through Supplemental Social Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid waivers and others (NIMH, 2009).

Some people open their homes for long-term care to unrelated adults. These are considered foster homes. Another type of home outside of the family is skill development homes. These homes are similar to foster homes but the

emphasis is on teaching self-care and housekeeping skills as well as arranging leisure activities (NIMH, 2009).

Supervised group living has become very popular for people with disabilities when the families are able to afford it. Group homes or apartments are staffed by professionals who will help the residents with basic needs like meal preparation, housekeeping and personal care needs. Some group homes are tailored towards those autistic individuals that are higher functioning (NIMH, 2009).

Lastly are institutions. The trend has definitely gone away from the placement of disabled people into institutions. There is a very negative connotation with the word *institution* because of the reputation brought forth from decades ago. This is still an option for those individuals that require constant supervision and intensive care but the system needs a complete makeover (NIMH, 2009). This will be discussed further in chapter five.

### Emotional Burden

In addition to the financial burden, having a disabled individual in the household can take an emotional toll on the family as well. Reports say that the divorce rate for couples with a disabled child is between 80 and 90 percent (Rudy, 2008a). There are a myriad of emotions that a parent may feel: anxiety, frustration, sadness, loss, guilt and anger are a few. Parents are frustrated with the daily demands of autism and feel as if they have no support system within their community. Parents are also saddened by the changes in their life plans as a result of having a child with autism (autism-help.org, 2009).

Research also shows that siblings of children with a disability can be negatively impacted as well. Siblings can sometimes be jealous of their autistic sister or brother or embarrassed by their behavior or condition. Siblings can also be extremely protective. Sometimes they realize at a very young age that they may be responsible for their affected sibling in adulthood and that can lead to many different emotions as well (autism-help.org, 2009).

### Summary

This chapter gives a glimpse into the lives of autistic individuals and their families. It also describes the struggles that families have in providing care for their affected loved ones. Additionally, the chapter outlined the efforts made by the government in providing services and highlighted some of the areas where there is a great need for change. The next chapter will outline Barack Obama's health care plan as well as explore the promises that he has made in relation to the autistic population. There are three areas that will be focused on in detailing Obama's intentions for the autistic population: insurance coverage, research funding and programs for autistic adults.

## **CHAPTER III**

### **PRESIDENT BARACK OBAMA'S HEALTH CARE REFORM**

President Barack Obama promised to make health care services available to every American. When he took office, however, the country was in a bona fide recession. Unemployment rates had increased drastically, the stock market was crashing and people were losing their homes because they could not afford their mortgages. Former Federal Reserve Chairman Alan Greenspan says the financial state of the country was as dire as he had ever seen in his long career (Stein, 2008).

Obviously, the plan to reconstruct the health care system would “take a back seat” to the failed economy. With more time to think about the Obama health plan, Americans have the opportunity to educate themselves on what these changes will mean to families, taxpayers, society and the country as a whole. Now that the emotion behind the election has dwindled, the plan needs to be looked at objectively in order to decipher who is going to fare well under the plan and who may be left out.

#### **Barack Obama on Health care**

From the onset of the election, Barack Obama has used the idea of “change” from the old administration and the old ways of government as a focal

point. One of the major areas of attention during the campaign was health care. Generally, the Democrats support the implementation of universal health coverage while the Republicans seemed to favor the traditional approach to health care for Americans. Obama's plan seems to be a combination of the two. He wants to mandate insurance for children and develop a public plan to cover more Americans; however, he says that he thinks that families that are content with their insurance companies should be able to keep their coverage (Obama, 2009a).

There are some very basic goals in President Obama's health care plan. According to the President's website, he plans "to provide affordable, accessible health care to all." In attempting to achieve this goal, there are some issues with the current system that he addresses. First is the skyrocketing of health care costs. The second issue is the need to expand coverage for all Americans and the last is the need to promote prevention and strengthen public health in the United States (Obama, 2009a).

There are some statistics that support the problems in which he intends to work on within the health care system that are outlined in the introduction of the President's health care plan. They are:

1. Health insurance premiums have doubled over the last eight years, rising 3.7 times faster than wages during the same time frame;
2. Over half of all personal bankruptcies are due to medical bills;
3. About 100,000 Americans die from errors in hospitals every year;

4. One-quarter of all medical spending goes to the administrative and overhead costs of health care and the reliance on antiquated paper-based medical record systems and information systems contributes greatly to these costs;
5. Over 45 million Americans, including over 8 million children, lack health insurance;
6. Eighty percent of the uninsured are in working families; and
7. Only four cents of every health care dollar is spent on preventative health and public health programs (Obama, 2009a).

#### Cost Reduction

When outlining the plan of action, there are four main areas for cost reduction that are mentioned in the health care plan. First, the Obama plan will improve efficiency and lower costs by investing in electronic health information technology systems. Since most medical records are still being printed on paper, it is becoming increasingly difficult to coordinate care for a patient and the current system lends itself to medical errors. Processing paper claims takes twice as long as electronic claims, therefore wasting valuable manpower and health care dollars. President Obama plans to invest \$10 billion a year over the next five years to improve these systems hoping to eventually save \$77 billion a year through “improvements such as reduced hospital stays, avoidance of duplicated or unnecessary services, more appropriate drug utilization and other inefficiencies” (Obama, 2009a).

The second cost reduction issue in the Obama plan is the need for better access to prevention and proven disease management programs. Over 75 percent of all health care dollars are spent on patients with one or more chronic conditions such as diabetes, heart disease and high blood pressure (Anderson, Herbert, Johnson & Zeffiro, 2004). All of these conditions have the potential to be prevented or managed successfully should the patient have access to the necessary programs. Obama will “require that plans that participate in the new public plan, Medicare or the Federal Employee Health Benefits Program (FEHBP) utilize proven disease management programs” (Obama, 2009a).

They would also like to see the implementation of medical home programs that will improve coordination of care for those with chronic conditions. One of the major ideas behind Obama’s plan for the country is the idea of complete transparency; this includes the health care arena. Obama would like to see complete transparency when it comes to quality and costs so that patients have access to more accurate information and can make informed decisions (Obama, 2009a).

Quality is the next area of concentration for cost reduction in the Obama health plan. To improve the quality of care they will promote patient safety by requiring providers to report preventable medical errors and develop programs to help practices and providers prevent these areas in the future. They will align incentives for excellence by implementing a “pay for performance” system for those providers that are seeing patients from the new public plan, the National Health Insurance Exchange, Medicare and FEHB. Additionally, the

administration would also like to see an increase in research for improving effectiveness (Obama, 2009a).

Health disparities are a major issue in health care and the President plans to address the problem by requiring hospitals and health plans to “collect, analyze, and report health care quality for disparity populations and holding them accountable for any differences found; diversifying the workforce to ensure culturally effective care; implementing and funding evidence-based interventions, such as patient navigator programs; and supporting and expanding the capacity of safety-net institutions, which provide a disproportionate amount of care for underserved populations with inadequate funding and technical resources” (Obama, 2009a).

The last point under improving the quality of care that the President’s plan mentions is the need to reform medical malpractice while preserving the rights of the patient. The increasing cost of medical malpractice insurance is affecting the amount of doctors that are practicing medicine and therefore raising the costs for everyone. Obama plans to improve antitrust laws to remedy this problem (Obama, 2009a).

The third point for cost reduction under the plan is to lower costs by taking on anticompetitive actions in the drug and insurance companies. The problem with the drug companies is that there is a small group of large companies that monopolizes the market. There have been 400 health care mergers in the last 10 years and just two companies control a full third of the national market (Obama, 2009a).

Premiums have increased over 87 percent in the last six years and in the same time, insurance administrative overhead has been the fastest area of health care spending. While families continue to struggle with rising costs, the CEOs of these insurance companies continue to receive multi-million dollar bonuses. Barack Obama will force insurers to pay out a reasonable share of their premiums for patient care instead of keeping exorbitant amounts for profit and administration. Increased competition for insurers is part of the National Health Insurance Exchange included in the plan (Obama, 2009a).

Another area that the President plans to reform is Medicare abuse. Independent reports show that on average the government pays 12 percent more than it costs to treat patients under Medicare Advantage as compared to those under the regular Medicare plan. This costs the government billions of dollars a year and leads to fraudulent abuse of seniors so they plan to eliminate the excessive subsidies and pay them the same amount that it would cost to treat the same patients under regular Medicare (Obama, 2009a).

Obama's plan will allow consumers to import safe prescription drugs from other countries. The purpose is to drive up competition within the United States so that drug companies are not overcharging the consumer. There will also be more regulation to ensure that generic drugs are not blocked from the consumer. Finally, Medicare will be able to negotiate for cheaper drug prices, and with the savings, the government would be able to invest more money in improving health care coverage (Obama, 2009a).

The fourth and final cost reduction strategy in the Obama health plan is to reduce the cost of catastrophic illnesses for employers and employees. Because having an employee with a catastrophic illness can be expensive for an employer, the price for all employees in the company increases. The President's plan is to reimburse employer health plans for a portion of the catastrophic costs over a designated amount if the company promises that the savings will be used to reduce the costs for the other employees (Obama, 2009a).

#### Affordable, Accessible Coverage Options for All

The plan for better coverage was designed with the intention of building on the current insurance system while leaving Medicare intact for those that rely on its services. The plan states that "under the Obama plan, Americans will be able to maintain their current coverage, have access to new affordable options, and see the quality of their health care improve and their costs go down" (Obama, 2009a).

The seven points for expanded coverage are:

1. Guaranteeing eligibility for all health insurance plans;
2. Creating a National Health Insurance Exchange to help Americans and businesses purchase private health insurance;
3. Providing new tax credits to families who can not afford health insurance and to small businesses with a new Small Business Health Tax Credit;
4. Requiring all large employers to contribute towards health coverage for their employees or towards the cost of the public plan;

5. Requiring all children to have health coverage;
6. Expanding eligibility for the Medicaid and SCHIP programs; and
7. Allowing flexibility for state health reform plans (Obama, 2009a).

#### Promoting Prevention and Strengthening Public Health

Barack Obama is putting the responsibility for public health on each and every person/entity in the United States, including the employers, school systems, workforce, individuals and families, and the federal, state and local governments. Their plan carefully outlines what they expect from each entity in the way of promotion and prevention (Obama, 2009a).

#### Financing the Health Plan

President Barack Obama sent Congress a budget that would boost taxes on the wealthy and slash Medicare to make way for a \$634 billion down payment on his health care plan (Crutsinger, 2009).

Obama's plan proposes achieving \$634 billion in savings on projected health care spending and diverting those resources to expanding coverage for uninsured Americans. This amount represents a little more than half the money that would be needed to extend health insurance to all of the 48 million Americans now uninsured (Crutsinger, 2009).

#### The 2008 Election and Autism Spectrum Disorders

The election in 2008 was historic for many reasons including the fact that for the first time autism was a key issue. In addition to Barack Obama, Senator Hillary Clinton also brought some much needed attention to the topic. Ever the health care champion, she and her husband, Bill Clinton, have been very vocal

on prominent health care issues from before he was elected to the presidential office in 1992. As a matter of fact, in the 2008 election, Clinton arguably gave autism the most attention of all the candidates (Pitney, 2007).

In November of that year, she announced that she would spend \$700 million a year on research, teacher training, and support services for autism. Clinton said that not enough was known about “one of the most urgent and least understood challenges” faced by the nation and that the U.S. is not prepared to deal with it. It was the first time that autism was mentioned as a priority for the government and included as part of the proposed budget (Pitney, 2007).

#### Barack Obama and Autism Spectrum Disorders

Every candidate had a website during the primaries but Barack Obama was one of the few that designated an entire page to autism spectrum disorders and the steps that he plans to take to help with the cause. Barack Obama plans to appoint a federal ASD Coordinator to oversee all federal ASD efforts, including research, support for families, awareness, and training for medical professionals. The coordinator will work with the states to ensure collaboration among federal, state and local agencies (Obama, 2009c).

Barack Obama did support the Combating Autism Now Act of 2006 but the federal funding has not increased to levels authorized by the act yet (Obama, 2009c). Obama supports IDEA, another act that has not been fully funded, forcing schools to deny services to children that need them. They plan to fully fund the acts as well as change the definition of “autism” to Autism Spectrum

Disorders to that all children that fall on the spectrum are able to get services (Obama, 2009b).

Lastly, Obama supports universal screening for infants and toddlers. Only half of the states screen all infants for the recommended 29 disorders. Part of their health care plan is to implement universal screening for babies at birth and then again at two years old. Universal screening is a crucial step in detecting and treating potentially life threatening illnesses. For autism spectrum disorders, early intervention is paramount for the child's development (Obama, 2009b).

### Summary

This chapter gives a clearer picture of what Obama envisions for the health care system of the U.S. and an idea of what he says he would like to achieve for the autistic population. The following chapter will analyze the plan for autism spectrum disorders, highlighting aspects of Obama's legislative history and gaps in his proposed health care reform.

## **CHAPTER IV**

### **ANALYSIS OF OBAMA'S HEALTH CARE PLAN**

There are some major changes that President Barack Obama is bringing to the country. In the first couple weeks of his administration, he implemented a stimulus plan to help bring the United States out of recession and unveiled his health care plan. Clearly, the President is not afraid to take chances in order to achieve big.

However, when it comes to health care, President Obama and his administration appears to be looking at the “big picture” when it comes to changing the health care system in the U.S. and not considering the impact on special needs groups. This chapter will analyze Obama’s health care plan with regard to autism spectrum disorders in the three areas previously discussed: insurance coverage, research towards a cure and programs for autistic adults.

#### Obama’s “Universal” Health care Plan

Under Obama’s public plan, everyone will supposedly have access to health care services regardless of age, preexisting conditions or health status (Obama, 2009a). In the beginning of his campaign, the plan was described as “universal health care,” but as time passed, those words were no longer used to describe the plan. One main reason for the distinction is that experts believe to

obtain true universal health care, there must be a mandate put in place. Obama rejected the mandate, except for children. He believes that Americans *want* health coverage but they can not *afford* health coverage so imposing a mandate on the public would be pointless (Gerstein, 2009). Opponents have also brought attention to the belief that if Obama's plan was implemented, there would still be approximately 15 million people without insurance (Kaiser Daily Health Policy Report, 2008).

The part of his plan that resembles universal health care is the public plan. Assuming that this part of his plan follows the same guidelines as universal health care, there are some important points to bring up in general and with regards to the autistic population.

#### Criticisms of Universal Health care

One of the most popular criticisms of universal health care is that it actually reduces access to health care services due to long wait times. This is thought of as "rationing" health care services. Britain's Department of Health reported in 2006 that at any given time, nearly 900,000 Britons are waiting for admission to National Health Service hospitals. In Canada, people that need urgent surgeries are often forced to seek treatment in the United States where they then have to pay out of pocket for the services (Cannon & Tanner, 2007).

Another prominent criticism relates to the shortages in the medical workforce due to the influx of patients and the poor compensation for medical professionals. In Britain, shortages of medical personnel, including physicians, force the cancellation of more than 50,000 operations each year. In Sweden, the

wait for heart surgery can be as long as 25 weeks, and the average wait for hip replacement surgery is more than a year. Many of these individuals suffer chronic pain, and judging by the numbers, some will probably die awaiting treatment (Cannon & Tanner, 2007).

Lastly, opponents feel that universal health care leaves the system without a market mechanism. It is believed that this will slow, if not stop, innovation in treatments and research (A. Reynolds, 2002).

#### Coverage for Autism under Universal Health care

While there is some speculation as to what is deemed “necessary” for an autistic individual, there is a tremendous amount of literature in support of various therapies. Physical therapy, occupational therapy, speech and ABA are the four main treatment methods sought by families struggling with autism (Rudy, 2009).

Politicians touting the praises of universal health care say that all Americans will have coverage but there has been no specific information about what services will be covered under the new plan. Autistic patients need more services than what that will be provided by the government as part of the basic coverage.

Canada is probably the best known example of universal health care. In Canada, ABA is not covered under the health care system. This means that families are forced to pay out-of-pocket for ABA. Autism advocates argue that this fact alone proves that the health care system in Canada can not be considered truly universal (Autism Reality NB, 2007).

The theory of universal health care is commendable but it seems to be an unreachable goal for the United States. The autistic population is a great example of a group that requires extensive medical services for improved quality of life; services that are expensive and scarce. It is unclear if any of these services will be covered under the President's plan.

#### Continued Research towards a Cure

All of the information that Obama included on his website with regard to funding autism research revolved around the Combating Autism Act which has already been passed and has not made much difference in the lives of the autistic population. On his website, the bill is not mentioned by name and it fails to mention that 2009, the year that he took office, is the third of the five years included under the act. There was no information found regarding how much funding has been released and where the money has gone thus far (Obama, 2009c).

Even if the Combating Autism Act were to be fully funded, the amount of money dedicated to research pales in comparison to the money spent on disorders that affect a smaller percentage of people (Moody, 2008). His plan shows no new proposal on how to increase federal dollars spent on research allocated specifically for autism.

#### Programs for Autistic Adults

Barack Obama has said continuously that he believes that people with ASDs can live independent and productive lives. He says that we have to work so that families understand and are able to support a family member with ASD

(Obama, 2009c). The rhetoric pulls at the emotions of Americans but there is no plan in place for adults with ASD. Over and over, Obama mentions IDEA and the changes that he will make to the act but this particular piece of legislation is geared towards children and not adults.

Obama's website states that he co-sponsors a measure that will expand federal funding for life-long services for people with ASD. The bill authorizes approximately \$350 million in new federal funding for programs for children and adults (Obama, 2009c). However, the "measure" that he is speaking of is the Senate Bill 937 Expanding the Promise of Individuals with Autism Act which is sponsored by Hillary Clinton. The bill was introduced in March of 2007, never went to vote, and subsequently, never became law (Govtrack, 2009). Whether or not the bill will be reintroduced in the next session remains to be seen but the effort is all but dead.

### Summary

To summarize the effect that Obama's health care reform would have on the autistic population is easy—none. Services that were not covered under the tradition health care system are still not going to be covered. Families will still be responsible for the financial burden of caring for a loved one with autism well into adulthood. Research is still going to be grossly under funded and there will still be a shortage of programs for autistic adults.

This chapter highlighted the vague areas and gaps in Obama's plan for health care reform with regard to autism. The next chapter will provide a blueprint for the ideal health care system for the autistic population. It will also

explain how health care administrators can make changes to the current system to ease the financial impact on the country that is inevitable with the aging of the autistic population.

## **CHAPTER V**

### **A BLUEPRINT FOR CARE**

The entire health care system needs to be reformed. There are many groups of the population that require extraordinary health care services that need to be considered when doing this. The autistic population is extremely relevant in health care reform because it represents a rapidly growing percentage of Americans that require large amounts of long term health care services.

The largest problem with the health care system when it comes to autism is the gap in services and care between childhood and adulthood. There is no denying that a cure needs to be found and that research should be a priority but something needs to be done for the families that are dealing with autism right now. There has to be a way to relieve the stress on these families while ensuring proper and affordable care to autistic individuals and a plan for their future.

In contemplating the ideal health plan for the autistic population, it is difficult to strike a balance between advocate and health care administrator. Assuming that President Obama's health care plan is implemented as it has been outlined; there are some recommendations that can be added to the plan that will better address the needs of the autistic population. Additionally, there

are some changes that can be made to the existing health system that could minimize the impact of the influx of special needs patients.

This chapter will attempt to provide a blueprint for change that will address the cost, quality and access of health care services for individuals and families struggling with autism, therefore addressing the concerns of an advocate and a health care administrator.

### Financial Assistance for Necessary Services

Under Obama's health reform, there will be a public plan that is offered by the government that is predicted to resemble Medicare but without the age requirement. In theory, this will increase the quantity of Americans that will have medical benefits. Providing more people with insurance serves no purpose if the people are not able to obtain services above and beyond routine health care.

People that need therapies and services that are not typically covered by insurance will still have to seek coverage in a private plan. Not only does this result in more expenses for the family but it does not guarantee access to the necessary treatments. All populations with cognitive, developmental or physical disabilities need access to a special needs plan.

Although Special Needs Plans (SNPs) were not developed with this particular population in mind, they do serve a very important purpose. SNPs were developed in 2003 to enroll certain subpopulations of the Medicare population. Enrollees are those that are dually eligible for Medicare and Medicaid, those that are residing in specified institutions for extended periods and those individuals with a specific severe or disabling chronic condition (CMA,

2008). “The three populations identified are the frailest, sickest, and most disabled beneficiaries. They are also the highest users of health care services” (CMA, 2008).

The number of this type of plan has grown tremendously over the last couple of years. In 2004, there were 11 SNPs approved by the Centers for Medicare and Medicaid Services (CMS) and by 2007, there were 476 approved that covered over 800,000 beneficiaries (CMA, 2008). The breakdown shows that there were 621,986 enrollees that were dually eligible, 139,761 enrollees that were institutionalized and 81,093 enrollees that had chronic conditions (CMA, 2008).

While SNPs are not designed for the autistic population, these plans serve as an example of a program that can be put in place for individuals that require extraordinary medical and therapeutic services. An SNP program could be offered for those that would like to have access to services above and beyond those offered in the public plan. Additionally, an SNP program would not necessarily have to be funded wholly through the government. SNPs could be made available through private insurers as well. The increased competition between the SNPs provided by the government and those developed by the private insurance companies would help to keep prices down and increase the quality of services. This would help contain costs for the government while providing an alternative for supplementing the public plan.

### Expansion of Medicaid

Obama has already stated that he intends to expand Medicaid. In doing this, there needs to be special emphasis put on Medicaid Autism Waivers. All states should be granted waivers and should be required to allocate a percentage of the federal funding received specifically to autism awareness, screening and treatment. Enrollment limits need to be increased to cover more individuals and the age limit should be eliminated so that adults are able to obtain autism services as well.

For each autistic individual eligible who receives Medicaid and the public plan, there should be a general autism voucher available to the families. The general autism voucher would be given to the families annually with no designated services attached; the families could use the voucher towards any approved therapies for their loved one. That way if a family wanted to divvy the allowance up to receive different types of therapy, they could, or they could dedicate the entire amount to one therapy they felt the individual needed at that particular time.

For example, an autistic individual may not need speech but if there is 20 sessions covered in their plan, then the family may be more likely to use the services anyway. If the family was able to use that coverage towards another therapy that the individual definitely needed, like ABA for instance, then the patient benefits more and the speech services are not wasted and can be available for an individual that really needs them. It makes for a more efficient system all around.

This works for the family because it subsidizes the treatment that they see fit for their autistic family member. This works for the government because it eliminates wasteful use of health care services. If families know that they are only getting a set amount as an allowance, then they will be more likely to use the allowance wisely. It also improves the chances that families will continue with services after the allowance is spent, possibly seeking coverage through an SNP, and will pump money into the private health care system.

#### Reallocation of Medicaid: Closing State Institutions

The greatest need is the need for programs for autistic and other special needs adults. More money should be allocated for finding safe places to house this population where they can live as independently as possible without burdening family members for their entire lives. Money that is currently being funneled into state institutions, also called state schools, could be better used in constructing intermediate care facilities (ICFs) and developing autism resource centers.

While this reform should be enforced uniformly across the country, this section will focus on Texas specifically as an example of how reallocation of Medicaid dollars could help more people and save the state money. Texas currently has 10 state hospitals that house people with mental illness and 13 state schools that house children and adults that are considered “developmentally disabled.” There are some state schools that are specifically for juveniles ranging in age from 13 to 17. These institutions receive approximately 85 percent of their funding from Medicaid (D. Reynolds, 2001a).

Texas has more people in institutions than any other state. Still, according to the Texas Department of Mental Health and Mental Retardation there are approximately 7,600 people on waiting lists for mental health services and 25,000 Texans on a list for mental retardation services (D. Reynolds, 2004). Additionally, a study conducted in 2005 found that Texas was 48<sup>th</sup> out of the 50 states for per capita spending on community-based services for people with developmental disabilities. At the time of the study, there were between 28,000 and 40,000 people waiting for these services, some of them had been on the list for over 10 years (D. Reynolds, 2005).

In addition to the apparent inefficiencies in providing care, the state institutions have a reputation for abusing and neglecting the residents. In 2007 alone, there were 482 substantiated allegations of abuse and neglect (D. Reynolds, 2008a). Obviously, this is revolting considering that families trust their loved ones to the care of the state, but allegations and violations also cost the state millions of dollars in federal money. Mexia State School is the best example of costly violations. In 2001, allegations of sexual and physical abuse caused a freeze of federal funding to the tune of \$77,000 a day until the problems were corrected (D. Reynolds, 2001a).

Another cost for the state regarding these institutions is in the maintenance of the facilities. To bring the institutions campuses up to par, the state has to spend \$180 million over six years starting in 2001. This money was intended for things like updating the smoke detectors and replacing the emergency generators. Additionally, the turnover rate for institutions in Texas

has been as high as 82 percent in some places (D. Reynolds, 2001b). So it can be determined that the institutions in Texas are inefficient, outdated, dangerous, poorly managed, neglectful and abusive. It seems that the taxpayers' money could be better spent.

Texas needs to close the state institutions and use the money for autism resource centers and community-based intermediate care facilities. The state has already begun to accept proposals for privatizing the state schools and hospitals as well as looking into what may be gained by selling land and equipment. If Texas were to sell the land that the Austin State School and the Austin State Hospital rest on, for instance, it would bring in approximately \$85 million (D. Reynolds, 2003). If this land were sold to private investors that were interested in opening long term care facilities for the special needs population, then the financial burden on the state would be greatly reduced and access to services would be increased.

Texans are in need of community-based services and intermediate care facilities. There are many ICFs in the state that are licensed to house between 6 and 13 people. Most are privately owned but there are couple that are government based (DADS, 2009). With the influx of special needs adults, there will need to be more facilities with greater capacity.

The cost for housing a person in a state-run facility is approximately \$120,000 annually or \$335 a day, while the cost for a community-based intermediate care facility is about \$165 a day (D. Reynolds, 2008b). That means that Texas could double the amount of special needs individuals that receive

service by simply reallocating the money from institutions to ICFs and other community-based programs.

### ASD Resource Centers: an Advocate's Standpoint

A major idea behind Obama's health plan is better coordination of care. This is not going to be achieved for the autistic population without making an investment in the areas of prevention, treatment and planning. This goal could be achieved by the introduction of autism-specific outpatient resource centers. These ASD resource centers could provide OT, PT, Speech and ABA under one roof making it easier for the patient and the family to coordinate health services. Other services for the individual and family matters could be provided as well such as counseling, sensory integration consultations, nutritional services, vocational training, respite care and financial planning services. These centers could serve as "one stop shopping" for autism services.

Counseling for parents and siblings of an autistic individual could help ease the burden on those living with an autistic individual. Group counseling where families could meet others that are struggling with the same issues could help family members adjust to the demands of caring for an autistic individual. Additionally, the opportunity to have face-to-face time with professionals that specialize in autism related issues could prove as a valuable resource for families in designing education plans and planning for the future.

Sensory integration is a constant challenge for people that are involved with autistic individuals. SI consulting for home, school and medical offices would give an idea of how to create the most comfortable setting for an autistic

individual. Also, SI consultations could help families, educators and medical personnel understand how to handle a "melt down" when an autistic individual becomes over-stimulated.

Nutrition is a vital part of treatment for a person with any medical condition, but even more so for an autistic individual. Autistic individuals have problems digesting certain foods and it is believed that gluten and casein have a behavioral effect as well (AutismWeb, 2009). Nutrition counseling could help families, school systems and medical professionals understand the special dietary needs of an autistic individual and help them familiarize themselves with healthy alternatives.

Respite care is needed by every caregiver at one point or another. It can be difficult for a caregiver to have even a part-time job which impacts the family financially. It can also be difficult for a caregiver to remain patient when dealing with the constant needs of an autistic individual. The ability to run errands without the patient or to work three mornings a week is taken for granted by most people but may seem to be a luxury for caregivers of autistic individuals. Respite care gives relief to the caregiver and gives them the opportunity to accomplish goals during the day.

Higher functioning autistic patients need access to vocational training. These individuals could learn a trade through the center and have the opportunity to contribute to society. The money that he or she would earn could offset the costs of the treatment for the family and give the individual a purpose in the community.

Arguably the most needed service for autistic families is financial planning. Financial planning services could help families make arrangements for autistic adults to enter group homes or assisted living facilities when the need comes. This service is necessary in order to provide the best possible alternative for residence and care as well as ease the financial and emotional burden of other family members or guardians.

#### ASD Resource Centers: an Administrator's Standpoint

ASD resource centers would be expensive to develop and implement. Health care officials need to approach the project as an investment. With the proper attention now, the country can avoid unnecessary expenses in the future. Additionally, access to health care services and other important resources could help autistic individuals reach their fullest potential and allow families the opportunity to have some control over choices for their future.

With appropriate planning, the family will be assured that their autistic loved one will have a place to live and receive necessary health care services. This keeps autistic individuals from ending up in institutions and becoming a financial burden on the state, or ultimately the taxpayers. Treating people in communities is far less expensive than treating them in institutions. In the case of the mentally ill, the total treatment cost per person per year, including the cost of housing, was \$60,000 compared to \$130,000 for institutional care (MHA, 2009). It can be assumed that the costs would be comparable to those necessary for the care of an autistic individual.

### Increased Medical Workforce Specializing in Special Needs

The implementation of Obama's health plan means that there may be more of a shortage in health care professionals across the board. To transition successfully, the medical workforce needs to be increased tremendously. With the surge of special needs patients, there will be demand for OTs, PTs, speech therapists and ABA specialists.

The shortage will be difficult to remedy because it comes at a time when educational requirements have increased in these fields. Physical therapists now must obtain a doctorate and occupational therapists and speech therapists must have a master's degree. Education is just getting too expensive and in the country's current financial situation, education could almost be considered a luxury. Additionally, there is a reluctance to enter the field because of lower salary expectations under "universal health care."

The health care system needs to learn from the experience of the education system. There are shortages in teachers, especially special education teachers that have caused schools to be overcrowded and have negatively impacted the level of education provided (Chaika, 2006). The health care system should follow the lead of the education system in implementing a program that reimburses or forgives medical professionals for some or all of their loans if graduates serve a designated amount of time in health care settings where there are shortages.

### Research as a Priority

Regarding research, there is always going to be a need for more money allocated to the causes and cure for the various ASDs. However, there needs to be a streamlining of the research efforts under a governing board. The majority of scientific research is funded by government grants, companies doing research and development, and non-profit organizations. This means that every person contributes to the cost of research through taxes, purchase of products or donations. So, this also means that the government needs to be accountable for the way research dollars are spent. Complete transparency of research funding is necessary.

### Summary

To recap the blueprint for care for the autistic population, an outline of the plan is provided. For those that are able to afford supplemental coverage and would like to have services above and beyond what would be offered in Obama's public plan, the government and private insurers will need to develop special needs plans. Special needs plans will be paid for by the patient or the patient's family.

Medicaid needs to be expanded to cover more people and states need to be given Autism Specific Medicaid Waivers to allow them to use government funding for prevention, awareness, education, and treatment for autism spectrum disorders. This will benefit all families that will be Medicaid eligible.

Under Medicaid and the public plan, families should be given a general autism voucher to use towards any approved autism treatment. The voucher

would be renewed annually and once the voucher was exhausted, families would be responsible for additional health care services in excess of the designated amount. This benefits all families that are eligible for Medicaid and all that are covered under the public plan.

Next, state institutions need to be closed and the Medicaid money that has funded these facilities needs to be used for autism resource centers and intermediate care facilities. This would enable the states to provide care to more people and boost the private sector as well. Autism resource centers will coordinate care and provide services, like financial planning and respite care, for families as well as the affected individual. All people would have access to the autism resource centers regardless of type of coverage but would be expected to pay a copay depending on what plan the individual is under.

If Obama's plan is implemented as it has been designed, there will be a need for more health care professionals. The government is going to have to subsidize education or the shortages will continue to get worse and access and quality will be compromised. Under the blueprint for care, health professionals could have student loans forgiven if they work under the public plan for a designated amount of time.

Lastly, research money needs to be streamlined and better regulated. No gains can be made if valuable research dollars are wasted on redundant or irrelevant research. This should be a responsibility of the "autism czar" that Obama has said he will appoint. Everyone contributes to the funding of research

so the American people deserve complete transparency when it comes to how research money is allocated.

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## **CONCLUSION**

There is obviously no easy answer to reforming the health care system. As the country transitions into another administration, there are many different groups that will be vying for funding and pushing their agendas. The most significant obstacle is the current economic situation which will most likely remain the focus of policymakers through Obama's term in office.

The best case scenario is if health care continues to be a key issue and is considered in all future spending the government may do to bring the country out of the recession. In the meantime, advocates for the autistic community need to remain current on the policy and funding in order to be considered a priority once health care comes to the forefront again.

While President Obama has definite gaps on his health care plan when it comes to the special needs population, he can at least be commended for bringing awareness to the autistic population. Not much can be expected to change in the next four years but families of autistic individuals can find some solace in the fact that they are at minimum "on the radar." It is not enough, but for now it will have to do.

### Summary of Contributions

This report contributes to the overall knowledge of the struggle of caring for a family member with autism and other disorders. In doing so, much needed attention was brought to the burden placed on families attempting to increase the quality of life for the autistic individual.

The government has ignored the inevitability of a surge of long-term care patients in the near future and has left the families with no options for special needs adults. The legislation is vague and ineffectual. This analysis highlighted the fact that the special needs populations are not a priority with the government historically, and apparently not with the new administration either.

Additionally, this report attempts to interpret the rhetoric of Obama's health care reform statement to determine what changes were going to be made to improve health care for autistic individuals, a small percentage of the large group of people that are most vulnerable.

Lastly, a blueprint for a health care system that would meet some of the needs of the autistic population was outlined. The blueprint makes suggestions that could be done to satisfy the needs of the patient while keeping in mind the goals of a health care administrator.

### Future Research to be Considered

At the conclusion of this report, there were some topics that could be researched in the future that may help understand what the United States must do to plan for the influx of special needs population that will require long term

care. An analysis of how other countries have financed health care and residential services for their special needs populations may be helpful.

Another area of interest could be the responsibility of families to get genetic testing in order to prevent the passing on of hereditary disorders. Would a government mandated genetic test be considered ethical and would it affect the family planning decisions of the general population? Would the “preservation of the species” be an ethical argument for the retrieval of genetic information?

Another ethical question is in regards to the provision of assistance for the developmentally disabled. Is it ethical to expect parents of disabled children to provide all care for the child’s entire lives? Does society have an ethical obligation to aid in the care of disabled individuals? What if the parents knew the child was going to be disabled during the pregnancy and decided to have the child anyway? Does that entitle them to the same level of government assistance as those families that were unaware they carried a genetic disorder?

These are just some of the ideas that could be explored further in determining the best way to prevent what conditions can be prevented and treat the special needs population with dignity and fairness.

## REFERENCES

- Abramson, L (2007). *Public schools prepare to educate kids with autism*. Retrieved on March 6, 2009, from <http://www.npr.org/templates/story/story.php?storyId=12776434>.
- Anderson, G., Herbert, R., Johnson, N., & Zeffiro, T. (2004). *Chronic Conditions: Making the Case for Ongoing Care*. *Robert Wood Johnson Foundation*. Retrieved on November 21, 2008, from <http://www.rwjf.org/pr/product.jsp?id=14685>.
- Autism Reality in NB (2007). *Facing autism in New Brunswick*. Retrieved in March 16, 2009, from <http://autisminnb.blogspot.com/2007/06/eugene-levy-senator-jim-munson-call-for.html>.
- Autism Speaks (2006). *White House Fact Sheet: Combating Autism Act of 2006*. Retrieved on September 25, 2008, from [http://www.autismspeaks.org/government\\_affairs/white\\_house\\_caa\\_facts.php](http://www.autismspeaks.org/government_affairs/white_house_caa_facts.php).
- Autism Speaks (2007a). *Autism Speaks announces multi-state insurance legislation campaign*. Retrieved on September 25, 2008, from [http://www.autismspeaks.org/government\\_affairs/multi\\_state\\_insurance\\_campaign.php](http://www.autismspeaks.org/government_affairs/multi_state_insurance_campaign.php).
- Autism Speaks (2007b). *Autism Speaks applauds Senator Hillary Rodham Clinton and Senator Wayne Allard for introducing the Expanding the Promise of Individuals with Autism Act of 2007*. Retrieved on September 25, 2008, from [http://www.autismspeaks.org/press/expanding\\_promise\\_act.php](http://www.autismspeaks.org/press/expanding_promise_act.php).
- Autism Speaks (2008). *Autism Speaks applauds Louisiana Governor Bobby Jindal for signing autism insurance reform legislation into law*. Retrieved on September 25, 2008, from [http://www.autismspeaks.org/press/governor\\_signs\\_louisiana\\_insurance\\_law.php](http://www.autismspeaks.org/press/governor_signs_louisiana_insurance_law.php).
- Autism Speaks (2009). *Facts about autism*. Retrieved on March 15, 2009, from <http://www.autismspeaks.org/whatisit/facts.php>.

- Autismhelp.org (2009). *The emotional journey of parenting a child on the spectrum*. Retrieved on March 17, 2009, from <http://www.autism-help.org/family-feelings-parents-autism.htm>.
- AutismWeb, (2009). *The truth behind the gluten-free, casein free diet for autism and PDD*. Retrieved on March 17, 2009, from <http://www.autismweb.com/diet.htm>.
- Barnhart, R. & Connolly, B. (2007, October). Aging and Down syndrome: Implications for physical therapy. *Physical Therapy*, 87(10). Retrieved on October 12, 2008, from <http://web.ebscohost.com.libproxy.txstate.edu/ehost/detail?vid=10&hid=112&sid=c6a6366d-8a01-4e17-a14b-d78ad17c5e65%40sessionmgr102>.
- Calvani, C. (2009). Carolina Journal Exclusives Growing number of autistic kids puts strains on public schools. *John Locke Foundation*. Retrieved on March 5, 2009, from [http://www.carolinajournal.com/exclusives/display\\_exclusive.html?id=5266](http://www.carolinajournal.com/exclusives/display_exclusive.html?id=5266).
- Cannon, M. & Tanner, M. (2007). Universal health care's dirty little secrets. *The Los Angeles Times*. Retrieved on March 7, 2009, from <http://www.latimes.com/news/opinion/la-oe-tanner5apr05,0,2227144.story>.
- Census Bureau (2008, August). *Health Insurance 2007*. Retrieved from <http://www.census.gov/hhes/www/hlthins/hlthin07/hlth07asc.html>.
- Center for Disease Control (CDC) (2004a). *Down syndrome prevalence at birth*. Retrieved on September 25, 2008, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/00032401.htm>.
- Center for Disease Control (CDC) (2004b). *Developmental Disabilities: Cerebral Palsy*. Retrieved on September 25, 2008, from <http://www.cdc.gov/ncbddd/dd/cp3.htm#common>.
- Center for Disease Control (CDC) (2005). *Developmental Disabilities: Intellectual Disability*. Retrieved on September 25, 2008, from <http://www.cdc.gov/ncbddd/dd/mr3.htm>.
- Center for Disease Control (CDC) (2006). *Down syndrome Survival Rate Increasing; Racial Disparities Exist in a Large Metropolitan Area*. Retrieved on September 25, 2008, from <http://www.cdc.gov/od/oc/media/pressrel/r060630.htm>.
- Center for Disease Control (CDC) (2007). *Autism Spectrum Disorders Overview*. Retrieved on September 25, 2008, from <http://www.cdc.gov/ncbddd/autism/overview.html>.

- Center for Medicare Advocacy, Inc. (CMA) (2008). *Medicare advantage special needs plans: What Congress needs to know*. Retrieved on September 22, 2008, from [http://www.medicareadvocacy.org/MA\\_07\\_07.19.MASNPs.htm](http://www.medicareadvocacy.org/MA_07_07.19.MASNPs.htm).
- Chaika, G. (2006). Scrambling for staff: The teacher shortage in rural schools. *Education World*. Retrieved on March 3, 2009, from [http://www.educationworld.com/a\\_admin/admin/admin142.shtml](http://www.educationworld.com/a_admin/admin/admin142.shtml).
- Choi, Y. (2004). Autism and the costs on the rise. *Autistic Society*. Retrieved on March 6, 2009, from <http://www.autisticsociety.org/News/article/sid=334--0-0.html>.
- Chozick, A. (2008). Obama tours single-payer system for health care. *The Wall Street Journal*. Retrieved on March 1, 2009, from <http://blogs.wsj.com/washwire/2008/08/19/obama-touts-single-payer-system/>.
- Collins, R., Davis, C., Doty, M., Kriss, J., & Schoen, C. (2006). Health coverage for aging baby boomers. *The Commonwealth Fund*. Retrieved on March 27, 2009, from <http://www.cmwf.org/Content/Publications/Fund-Reports/2006/Jan/Health-Coverage-for-Aging-Baby-Boomers--Findings-from-The-Commonwealth-Fund-Survey-of-Older-Adults.aspx>.
- Crutsinger, M. (2009). *Obama budget moves towards universal health care*. Retrieved on March 1, 2009, from [http://www.salon.com/wires/ap/us/2009/02/26/D96JAF4G3\\_obama\\_budget/](http://www.salon.com/wires/ap/us/2009/02/26/D96JAF4G3_obama_budget/)
- Dombeck, M. & Reynolds, T. (2006). *Autism and medication*. Retrieved on March 14, 2009, from [http://www.mentalhelp.net/poc/view\\_doc.php?type=doc&id=8792&cn=20](http://www.mentalhelp.net/poc/view_doc.php?type=doc&id=8792&cn=20)
- Douglas, L. & Martin, A. (2007). Health care expenditures associated with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine* 161(4). Retrieved on March 17, 2009, from <http://archpedi.ama-assn.org/cgi/content/full/161/4/350>.
- Dragow, E., Lowrey, K., & Yell, M. (2005). No Child Left Behind and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities* 20(5). Retrieved on November 21, 2008, from <http://depts.washington.edu/pdacent/archive/checkitout8.pdf>.

Fragile X Research Foundation (FRAXA) (2007). *How common is fragile X: Just one gene*. Retrieved on November 14, 2008, from [http://www.fraxa.org/aboutfx\\_cause.aspx](http://www.fraxa.org/aboutfx_cause.aspx).

Gerstein, J. (2009). It's not universal health care, but... *Politico*. Retrieved on March 15, 2009, from <http://www.politico.com/news/stories/0209/19292.html>.

GovTrack (2007). *Expanding the Promise for Individuals with Autism Act of 2007*. Retrieved on February 18, 2009, from <http://www.govtrack.us/congress/bill.xpd?bill=s110-937>.

Health Care for All California (HCA) (2009). *The crisis of our current health care system*. Retrieved on October, 12, 2008, from [http://www.healthcareforall.org/health\\_care\\_crisis.html](http://www.healthcareforall.org/health_care_crisis.html).

Johnson, C. & Myers, S. (2007). Management of children with autism spectrum disorders. *Pediatrics*. Retrieved on March 16, 2009, from <http://pediatrics.aappublications.org/cgi/content/full/peds.2007-2362v1>.

Kaiser Daily Health Policy Report (2009). *President Obama's Budget Proposal Includes Broad Changes to Health Care System*. Retrieved on March 11, 2009, from [http://www.kaisernetwork.org/daily\\_reports/rep\\_hpolicy\\_recent\\_rep.cfm?dr\\_cat=3&show=yes&dr\\_DateTime=02-27-09](http://www.kaisernetwork.org/daily_reports/rep_hpolicy_recent_rep.cfm?dr_cat=3&show=yes&dr_DateTime=02-27-09).

Kaminski, J. (2006). Insurance Coverage for Autism. *OLR Research Report*. Retrieved on March 5, 2009, from <http://www.cga.ct.gov/2006/rpt/2006-R-0793.htm>.

Losgdon, A. (2009). *Individuals with Disabilities Education Act: What is the IDEA?* Retrieved on October 23, 2008, from <http://learningdisabilities.about.com/od/publicschoolprograms/g/ideadefinition.htm>.

Martin, J. (August 14, 2008). Cost of caring for a child with special needs varies from state to state. *Washington State University in St. Louis*. Retrieved on October 8, 2008, from <http://record.wustl.edu/news/page/normal/12071/html>.

Mental Health Association in Greensboro (MHA) (2009). *Mental Health Facts*. Retrieved on February 14, 2009, from <http://www.mhag.org/linkstomhfacts.cfm>.

- Moody, J. (2008). The strategic plan for the Combating Autism Act. *Age of Autism*. Retrieved in February 21, 2009, from <http://www.ageofautism.com/2008/07/the-strategic-p.html>
- Myers, S. & Johnson, C. (2007, November). Management of Children with Autism Spectrum Disorders. *Pediatrics*, 120(5), Retrieved on November 14, 2008, from <http://web.ebscohost.com.libproxy.txstate.edu/ehost/detail?vid=7&hid=112&sid=c6a6366d-8a01-4e17-a14b-d78ad17c5e65%40sessionmgr102>.
- National Down Syndrome Society (NDSS) (2008). *About Down's syndrome*. Retrieved on October 8, 2008, from [http://www.ndss.org/index.php?option=com\\_content&view=article&id=54:down-syndrome-fact-sheet&catid=35:about-down-syndrome&Itemid=74](http://www.ndss.org/index.php?option=com_content&view=article&id=54:down-syndrome-fact-sheet&catid=35:about-down-syndrome&Itemid=74).
- National Institute of Mental Health (NIMH) (2009). Adults with an autism spectrum disorder. *National Institutes of Health*. Retrieved on February 21, 2009, from <http://www.nimh.nih.gov/health/publications/autism/adults-with-an-autism-spectrum-disorder.shtml>.
- National Institute of Neurological Disorders and Stroke (NINDS) (2006). Autism Fact Sheet. *National Institutes of Health*. Retrieved on September 7, 2008, from [http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm).
- Neurology Channel (2008). *Cerebral palsy: Overview, types, incidence and causes*. Retrieved on October 8, 2008, from <http://www.neurologychannel.com/cerebralpalsy/index.shtml>.
- Obama, B. (2009a). *Barack Obama and Joe Biden's Plan for a Healthy America: Lowering Health Care Costs and Ensuring Affordable, High-Quality Health Care for All*. Retrieved on October 12, 2008, from [http://www.barackobama.com/pdf/issues/Health careFullPlan.pdf](http://www.barackobama.com/pdf/issues/Health%20careFullPlan.pdf).
- Obama, B. (2009b). *Barack Obama and Joe Biden's Plan to Empower Americans with Disabilities*. Retrieved on October 12, 2008, from <http://www.barackobama.com/pdf/DisabilityPlanFactSheet.pdf>.
- Obama, B. (2009c). *Barack Obama and Joe Biden: Supporting Americans with Autism Spectrum Disorders*. Retrieved on October 12, 2008, from <http://www.barackobama.com/pdf/AutismSpectrumDisorders.pdf>.
- Pitney, J. (2007). Autism and presidential politics. *Britannica Blog*. Retrieved on October 12, 2008, from <http://www.britannica.com/blogs/2007/12/autism-and-presidential-politics/>.

- Reynolds, A. (2002). No health insurance? So what? *CATO Institute*. Retrieved on March 16, 2009, from <http://www.cato.org/research/articles/reynolds-021003.html>.
- Reynolds, D. (2001a). Mexia State School is close to decertification, again. *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Reynolds, D. (2001b). State schools appeal directly to voters for funding. *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Reynolds, D. (2003). Eeney, meeney, miney, moe—which institutions should we close? *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Reynolds, D. (2004). Texas lawmakers want study on closing institutions. *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Reynolds, D. (2005). Texas families continue to wait for community services. *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Reynolds, D. (2008a). Reports of abuse in state schools on the rise. *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Reynolds, D. (2008b). Texas state schools ignore requests to move to community, but hired workers with abusive pasts. *Inclusion Daily Express*. Retrieved on March 17, 2009, from <http://www.inclusiondaily.com/news/institutions/tx/lead.htm>.
- Rudy, L. (2007a). *Occupational therapy and autism: The Basics*. Retrieved on December 27, 2008, from <http://autism.about.com/od/whatisautism/a/OTBasics.htm>.
- Rudy, L. (2007b). *Physical therapy and autism: The Basics*. Retrieved on December 27, 2008, from <http://autism.about.com/od/autismtherapy101/a/PTbasics.htm>.
- Rudy, L. (2008a). *Does autism in the family lead to divorce?* Retrieved on February 21, 2009, from <http://autism.about.com/b/2008/10/13/does-autism-in-the-family-lead-to-divorce.htm>.

- Rudy, L. (2008b). *Speech therapy for autism: The Basics*. Retrieved on December 27, 2008, from <http://autism.about.com/od/whatisautism/a/SLP.htm>.
- Rudy, L. (2009). *Top Ten Treatments for Autism*. Retrieved on December 27, 2008, from <http://autism.about.com/od/treatmentoptions/tp/topdevandbehav.htm>.
- Saffran, R. (2007). *What is applied behavior analysis? ABA Resources: Autism, PPD, Hyperlexia*. Retrieved on December 27, 2008, from [www.rsaffran.tripod.com/whatisaba.html](http://www.rsaffran.tripod.com/whatisaba.html).
- Spigel, S. (2007). Medicaid autism waivers and state agencies serving people with autism. *OLR Research Report*. Retrieved on March 6, 2009, from <http://www.cga.ct.gov/2007/rpt/2007-R-0319.htm>.
- Stein, S. (2008). Greenspan: This is the worst economy I have ever seen. *The Huffington Post*. Retrieved on March 26, 2009, from [http://www.huffingtonpost.com/2008/09/14/greenspan-this-is-the-wor\\_n\\_126274.html](http://www.huffingtonpost.com/2008/09/14/greenspan-this-is-the-wor_n_126274.html).
- Texas Department of State Health Services (2007). *Children with Special Health Care Needs (CSHCN) Program Health Benefits*. Retrieved on September 25, 2008, from <http://www.dshs.state.tx.us/cshcn/benefits.shtm>.
- United States Department of Education (2004). *Special education and rehabilitation services: The Rehabilitation Act*. Retrieved on November 14, 2008 from <http://www.ed.gov/policy/speced/reg/narrative.html>.
- United States Department of Health and Human Resources (HHS) (2002). Closing the gap: A national blueprint to improve the health of persons with mental retardation. *Surgeon General's Conference on Health Disparities and Mental Retardation*. Retrieved on November 14, 2008 from <http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>.
- Work World (2009). Developmental Disabilities Assistance and Bill of Rights Act (DD Act). *Employment Support Institute School of Business Virginia Commonwealth University*. Retrieved on September 25, 2008, from [http://www.workworld.org/webhelp/developmental\\_disabilities\\_assistance\\_and\\_bill\\_of\\_rights\\_act\\_dd\\_act\\_.htm](http://www.workworld.org/webhelp/developmental_disabilities_assistance_and_bill_of_rights_act_dd_act_.htm).

## APPENDIX A

### AUTISM-SPECIFIC MEDICAID WAIVERS

	<b>Colorado</b>	<b>Indiana</b>	<b>Maryland</b>	<b>Wisconsin</b>
Date of Waiver	2006	2002	2001	2004
Administering Agency	Health Care Policy & Financing Agency	Bureau of Developmental Disabilities	Department of Education	Bureau of Long-Term Services in Health & Family Services Dept.
Age Range	0-6	0-22	0-21	0-22
Eligibility	Autism, but not Asperger's or PDD/NOS*	Autism, but not Asperger's or PDD/NOS*	Autism, including Asperger's and PDD/NOS*	Autism, including Asperger's and PDD/NOS*
Financial Eligibility	Medicaid-eligible; parents' income included	Medicaid-eligible; parents' income excluded for children under 18	Medicaid-eligible; parents' income excluded	• Medicaid-eligible; parents' income excluded
Services Provided	Behavior, occupational, & speech therapy; psychological services	<ul style="list-style-type: none"> <li>• Autism-specific services: Applied behavior analysis, community transition support, person-centered &amp; individualized support planning</li> <li>• Also eligible for broader range of services under DD waiver</li> </ul>	Intensive, in-home individual support; respite care; family training; residential habilitation; supported employment; therapeutic integration (after-school); targeted case management	<ul style="list-style-type: none"> <li>• Autism specific: Intensive, in-home autism treatment (20-35 hours/wk) for 3 years</li> <li>• Also eligible for broader range of services under DD &amp; mental health waivers</li> </ul>
Enrollment & Cost Caps	75; \$ 25,000 a year	400	None, but enrollment currently closed	None, but enrollment currently closed
Number Served (year)	75 (2007)	334 (2007)	900 (2005)	250 (2007)

## **VITA**

Cecelia Drake Cavallario is from San Marcos, Texas. She is the daughter of Terry and Carol Drake and is the middle child of nine children. She graduated from San Marcos High School in 1994 and obtained her Bachelor of Healthcare Administration from Texas State University-San Marcos in 2003. After a two year adventure in New York City, Cecelia returned to Texas to work on her Master's in the same field. She and her sisters have begun a central Texas chapter of FRAXA, a non-profit organization that is dedicated to raising money for research towards Fragile X Syndrome and autism, which has affected their family. Cecelia entered the Graduate College of Texas State University-San Marcos in August 2006, where she met her husband David. They live in San Antonio with their beautiful baby boy.

This thesis was typed by Cecelia D. Cavallario.

