Autism as a Social Problem

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Abstract

The purpose of this paper is to analyze autism as a social problem. An overview of the history of abnormal psychology and the treatment of individuals considered abnormal is presented as autism was originally generalized as an abnormal psychological condition. The societal perceptions of mental illness are presented. The historical background of autism specifically is explored and compared to the historical perspective of the United States when the autism was recognized as a social problem. The political and cultural environment of the time will be discussed. The diagnosis and treatment of Autism and the other challenges of families affected by autism is discussed. Further, the recognition of autism as a social problem and development of policies and programs to assist families coping with autism is examined. Finally, the present state of autism as a social problem and the most current trends for the future is discussed.
An Analysis of Autism as a Social Problem

Autism is a relatively newly defined disorder that presents many frustrating challenges to the parents and families affected by it. The number of cases or awareness of cases is increasing:

In 2010, the federal Centers for Disease Control and Prevention estimated that an average of one in 110 children in the United States has an autism spectrum disorder. According to the group Autism Speaks, government figures also estimate autism diagnoses are increasing 10 to 17% annually (McCulloch & Martin, 2011, p. 27).

The challenges that face the parents of children with Autism are numerous. The first challenge stems from the lack of widespread, consistent information about the disorder. The lack of concrete information results in the tragedy of many children not properly diagnosed at an early age. This proper diagnosis is necessary at as early an age as possible so the individual affected by autism can receive effective treatment to create a better trajectory track to live a more productive life. In addition, the disorder has a wide range of manifestations and level of severity. Treatments vary greatly in effectiveness depending upon the individual and treatment can be very expensive. The cause is still debatable although the researchers tend to favor genetics and environmental factors, hence a cure is not known at this time. To complicate matters, the moral dilemma in regard to genetic testing and what action to take when affected genes are found.

This paper will present the early perceptions of society’s view of mental health and autism and will analyze the policies and resources that have developed from the disorder becoming recognized as a social problem in the United States.

Historical Overview of Psychological Practices

To better understand the history of Autism, an overview of psychological methods and ideologies must be explored as autism was thought to be a mental illness and eventually
associated with schizophrenia. Individuals affected by autism were treated the same as other forms of mental illness as a result of the misunderstood condition.

**The Origins of Abnormal Psychology and Mental Health**

The origins of abnormal psychology is thought to go back to ancient times when societies were thought to view events that they did not understand as produced by supernatural forces, such as the vengeance of God or evil spirits. References of people thought to be possessed have been found in the ancient records of the Chinese, the Egyptians, the Hebrews, and the Greeks (Alloy, Riskin, & Manos, 2004). In the article by O’Connell (2001) the examples of demonic possession of the mentally ill are highlighted in the New Testament with Jesus curing the possessed along with the lepers, the blind, the deaf, and the lame.

The Greek physician Hippocrates (c.460-c. 360 BCE) is believed to be the first to set out to prove all illness to be of natural causes and is attributed with the birth of medical science. This also is thought to cause the shift in abnormal psychology from the supernatural to the scientific as Hippocrates set forth reforms after observations and recordings of mental illnesses of his time. During the time of the Middle Ages, the evidence shows that mental illness was treated as being caused by natural causes much as it done today. Such is the example given of one man who was said to have lapsed into insanity after a “blow received on the head” (Alloy, et. al., 2004).

During the Renaissance periods the pendulum swings back again toward more supernatural theories as evidenced in the treatment of many women in Western culture, whose behavior offended the Church, being accused of being witches and thus tortured and killed. It has been pointed out that some of the individuals accused of witchcraft were likely mentally ill as written by Reginald Scot in 1584 in his publication of *Discovery of Witchcraft* (Alloy, et. al., 2004).

**The Rise of Asylums**
The rise of the asylums has been said to have come about in the eighteenth century but the practice of hospitalizing the mentally disturbed was first evidenced as separate wards in general hospitals in the Arab countries. The first hospital exclusively for the mentally ill was in Spain in the early fifteenth century (Alloy, et al., 2004). This hospital must have been the forerunner to those that struggle to survive today. In the article by Gimmy and Baumbach (2001) the psychiatric hospitals are limited in their purpose but strive to provide moderately complicated medical treatment to those who need it. In the 1990s with the lawsuits of patients and insurers and rise in costs and decline in occupancies as well as oversupply and competition, the psychiatric hospitals faced hard times.

Early asylums were thought to be used primarily to house and isolate the mentally ill from the rest of society. Literature is full of horrific stories of the insane kept in chains and the uproarious “bedlam” that went on, much likely due to the ineffective treatments as well as the difficulty with the patients (Alloy, et. al., 2004). The reforms of Pinel and Tuke, who introduced humane treatment of the patients and created more therapeutic environments became widespread and were eventually named moral therapy. In America, Benjamin Rush is credited with influencing American psychiatry in the direction of humane therapy. Dorothea Dix further extended the practice across America and into Canada and Scotland and was responsible for founding and funding 32 mental hospitals (Alloy, et. al., 2004). Unfortunately, Dix also inadvertently contributed to the decline in moral therapy as hospitals needed bigger staffs and governments grew less inclined to fund for mental as opposed to physical health. Thus the staffs dwindled as the funding lessened and the whole tranquil atmosphere with individual care concept could not be fulfilled. In addition, the rise of the larger state mental hospitals came along at the same time as the rise of the medical model and early success convinced the psychiatric
professionals to direct their work toward more biological treatment as opposed to the psychological treatment of moral therapy. As attitudes changed and the luxury of moral therapy was frowned upon by some religions such as the Protestants moral therapy was replaced by custodial care as the mentally ill were less tolerated out in society in the second half of the nineteenth century. These intolerable people were sent away to live in institutions, thus giving rise to the social stigma that still exists with many people today. The treatment that these patients were inflicted with was presented in the 1975 film adaptation of the book written by Ken Kesey, starring Jack Nicholson, “One Flew Over the Cuckoo’s Nest.” Nicholson played a man who allowed his self to be placed in the institution to avoid harsher treatment in prison. Nicholson’s character’s rebellious antics were disruptive and he was administered a frontal lobotomy thus permanently destroying his personality and necessitating custodial care.

**The Trend of Deinstitutionalization**

At the same time as the horrors of the damage being done in institutions was being discovered, the effectiveness of calming medicines were proven, and the deinstitutionalization movement began and the number of mental patients in hospital dropped dramatically. This exodus gave rise to the new community mental health centers that could offer outpatient and inpatient care, some of which are in operation today.

While the hospitals spread so did the study of abnormal psychology throughout Europe and America with Wundt in Germany and his scientific experimentation with the precise methods of measures and controls as applied to human thought and behavior. Wundt’s student Kraepelin went on to found his own psychological laboratory devoted to the study of psychopathology or abnormal behavior (Alloy, et. al., 2004). Wundt is often credited to be the developer of modern psychology. Kraepelin and his biogenic theory classified mental illness
into separate pathologies that could be recognized by a syndrome thus diagnosed in the same manner that physical problems could be. Kraepelin’s theory led the way to the medical model, which is still in use today.

**Theories of Mental Health**

As the history of mental health unfolded, so did many theories. The biological view posits that the mental illness can be understood by the study of the biology bases of behavior, namely biochemical, genetic, physiological, and neurological (The Centre for Cancer Education, 1997 - 2007). The psychosocial theories refer to the psychological development of an individual, such as explained Erik Erikson and his stages, through the interactions in one’s social environment (Erikson, 1950). The theory of sociocultural models were first attributed to Lev Vygotsky and his “sociocultural theory of mind” and his theory of activity, which posits that psychological development is achieved through information processing of the social culture that influences the individual (Yasnitsky, & Ferrari, 2008). The combination of these theories is thought to be most useful in diagnosis and treatment. The biopsychosocial model of health is; based on social-cognitive theory. The biopsychosocial model implies treatment of disease processes requires that the health care team address biological, psychological, and social influences upon a patient's functioning. In a philosophical sense, the biopsychosocial model states that the workings of the body can affect the mind, and the workings of the mind can affect the body (Halligan & Aylward, 2006).

**The Birth of Autism as an Independent Mental Disorder**

The word Autism is derivates from the Greek word “autos,” or “self” thus reflected of the behavior of a person with autism with his lack of social interaction – or keeping to oneself
A number of doctors are credited with the birth of autism as its own independent mental disorder.

Eugene Bleuler (1857 – 1939)

The term Autism was first used by Swiss psychiatrist, Eugene Bleuler in 1912 in the American Journal of Insanity (Gaforgy, 2011). At the time of the publication by Bleuler, autism was thought to be just another form of schizophrenia due to the presentation of the lack of social skills to interact with others and the apparent self-absorption of the inflicted individual. Because the disorder was thought to be a type of schizophrenia, it was treated as such by researchers and mental health professionals until the 1960s (“History of Autism,” 2011). Hence, individuals suffering from autism were subjected to the same horrors of early abnormal psychology as other people thought to have a mental illness. It was not until the mid-1900s and the work of three other doctors when autism became the disorder as diagnosed today (Gaforgy, 2011).

Leo Kanner (1894-1981)

Leo Kanner is credited as one of the first child psychologists and first to recognize autism as its own mental disorder in 1943. Kanner, an Austrian-American psychiatrist who worked at Johns Hopkins Hospital in Baltimore, identified common traits among a study of 11 children who he diagnosed as suffering from early infantile autism. Kanner discussed the following traits:

“Social interaction difficulties

Difficulty processing and adapting to changes

Particularly good memory

Belated echolalia (repeating speech made by others)

Exceedingly sensitive to sounds, and other stimulants
Food issues

Good intellectual potential

He used the term autism to describe the main characteristics all the children he studied displayed—little to no interest in socializing with other people “(Gaforgy, 2011, p. 2). In the mid 1900s, the disorder was considered rare with “approximately 2-4 out of every 10,000 children” being affected by the disorder (MacFarlane & Kanaya, 2009, p. 662).

**Hans Asperger (1906-1980)**

Dr. Hans Asperger is best known for the condition known as Asperger’s Disorder, which is a specific type of autism displaying high functionality by the individual. In 1944, the scientist and pediatrician studied four young boys and noted that each boy displayed most of the same characteristics as the children in the study done by Kanner a year earlier. The differences were the lack of echolalia, the less graceful motor skills but also the boys spoke like adults. Unfortunately, Asperger’s findings were not widely disseminated until the late 1980s likely because the report was not translated into English before that time (Gaforgy, 2011).

**Bruno Bettelheim (1903 – 1990)**

A widely accepted theory, until recently, came from the work and book written by Dr. Bruno Bettelheim in 1967 called “The Empty Fortress” in which Bettelheim coined the term “refrigerator mother.” Bettelheim developed the theory that infantile autism was caused by mothers who presented as emotionally cold to their infants. This was considered the catalyst of autism for many years (Gaforgy, 2011).

**Treatment for Autism**

Once autism was thought to be a separate disorder from schizophrenia, the treatments in the 1960s through the 1970s were primarily electric shock, the use of medications such as LSD,
and techniques designed to change behaviors employing pain and punishment ("History of Autism," 2011). Policy makers created separate day schools and institutions for individuals affected by autism (Wolff, 2004).

During the 1980s and 1990s the use of behavior therapy emerged as the primary method of treatment with the use of highly controlled learning environments ("History of Autism," 2011).

Increasing awareness through the development of parents groups and the dissemination of publications helped advance the understanding of the public and health professionals in education and health care (Wolff, 2004; "History of Autism," 2011). The increased awareness and education led to better intervention and education but has also led to the seduction of desperate parents to embrace unproven, expensive, and ineffective treatments. These treatments “include facilitated communication, auditory integration, holding therapy, and a variety of dietary interventions (Wolff, 2004, p. 206). Today, the use of behavior and communication therapy such as Applied Behavioral Analysis (ABA) therapy and other complementary therapy in combination of vitamins and certain drugs is the primary mode of treatment in the U.S. Integration with other more neuro-typical children in school has seen promise as well (Wolff, 2004; "History of Autism," 2011). Treatment can be expensive. ABA therapy can cost from $60,000 to $80,000 a year (Dusenberry, 2009).

**Diagnosis of Autism**

The most effective treatment comes from intense early intervention; the earlier the intervention, the better trajectory will be for a more “normal” life for the child. Furthermore, there appears to be a “window of opportunity,” as behavioral therapies are substantially more effective prior to the age of 7. This requires a proper diagnosis, which can be troublesome,
depending on the doctor. Not all doctors are well educated in the early detection of autism, and many physicians take a “wait and see” approach, which costs patients and families valuable time which otherwise could have been spent in interventions (J. Kelderman, personal communication, November 14, 2011).

One of the major issues surrounding the diagnosis of autism is that methods of diagnosis are not precise in the way a diagnosis of measles is precise (Grandin, 2006). The diagnosis is made through use of behavioral observations, parent interviews, questionnaires, and/or standardized testing, and different doctors tend to interpret behaviors differently. Thus, some parents will receive different diagnoses for the same behaviors. The issues arise when diagnoses are confused, such as difficulties surrounding the similarities of Asperger’s, Social Anxiety, and/or Attention Deficient Hyperactivity Disorder (ADHD). The behaviors of a child with Asperger’s may be similar to a child with ADHD. There still needs to be more definitive brain imaging and laboratory testing for the diagnosis of autism (Grandin, 2006).

As parents of autistic children became educated and found their voice, the boundaries of autism expanded to include those individuals with Asperger’s syndrome to the more classic Kanner’s syndrome. The variability among phenotypes is increasingly appreciated. The conception of autism evolved into a more varied condition called Autism Spectrum Disorder (ASD) (“History of Autism,” 2011; Grandin, 2006; Wolff, 2004).

The diagnosis of autism has been further complicated as the criteria used by psychological professionals, the Diagnostic and Statistical Manual of Mental Disorders (DSM) did not include autism until the 4th edition in 2000. This 4th edition DSM or DSM-IV-TR is the manual that most psychology professionals use currently but the information pertaining to autism has increased greatly since 2000 (MacFarlane & Kanaya, 2009). The DSM-IV-TR specifies:
A total of six or more characteristics from three different sections for diagnosis. Specifically, the onset of Autism should be noticed by the age of three in the area(s) of social interaction, language for communication, and/or restricted, repetitive, and stereotyped patterns or behavior. The DSM-IV-TR also makes a clear distinction between Autism and Autism Spectrum Disorders (ASD), including Asperger’s Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), which have separate diagnostic criterions (MacFarlane & Kanaya, 2009, p. 662).

Education does not follow the same criteria to determine the qualifications for a child to receive special education. School administrators and practitioners follow the federally mandated criteria set forth by the Individuals with Disabilities Education Act (IDEA). To receive federal funding, the IDEA criteria must be followed but the states have some flexibility in setting the standards for educational eligibility for special education. The eligibility for special education does not require the expertise of a licensed clinical psychologist and the guidelines of the Code of Federal Regulations is used instead of the DSM-IV-TR (MacFarlane & Kanaya, 2009). The primary difference between the two methods of identification is that the level of a child’s impairment must affect educational functioning for benefits under the category of ASD. A high-functioning individual with autism may not be clinically diagnosed but may be eligible for special education under the autism category if evaluated by the educational committee (MacFarlane & Kanaya, 2009). The differences in diagnostic methods can affect the educational opportunities for a child. According to research in 2007, “approximately one-third of all children who were clinically diagnosed with Autism were not receiving special education services under the Autism category” (MacFarlane & Kanaya, 2009, p. 662).
It is now apparent that many of the most highly intelligent and most accomplished individuals in the realm of science, math, and technology could be diagnosed as being on the autism spectrum (Grandin, 2006). Temple Grandin is one prime example of a highly productive and accomplished individual who has contributed a great deal to society but who is also affected by autism. Other examples include Bill Gates and Albert Einstein (Kelderman, 2011).

**The Cause of Autism**

One of the earliest causes of autism was said to be bad parenting as evidenced by the writing of Dr. Bruno Bettelhiem (Gaforgy, 2011). This is not the case today but the cause of autism is still unknown. Research increasingly supports a genetic etiology for ASD, and others suggest environmental factors may contribute to varying degrees, at least for a minority of individuals with ASD (“History of Autism,” 2011; Wolff, 2004). A fervor surrounded the use of vaccines as a cause of autism. In one study published in 1998 in the British journal, *The Lancet*, Dr. Andrew Wakefield “suggested a link between autism and the measles, mumps and rubella, or MMR, vaccine” (Saunders, 2010, p. 38). This has led to lawsuits for redress and compensation as well as the refusal of vaccinations by parents of children with ASD (Wolff, 2004). According to current studies, the value of vaccines has been evidenced and the causal relationship between vaccinations and autism has not (McGuinness, & Lewis, 2010). The study was “recently retracted by the journal, and Wakefield was found guilty of serious professional misconduct by the General Medical Council of the United Kingdom” (Saunders, 2010, p. 38).

As it is not yet widely known as to the clear evidence at a young age as to which child will develop into a high or low functioning person with autism, although “signs are apparent as early as 3 to 6 months, and there is a new assessment coming out for infants, one must know what to look for” (Kelderman, 2011). There is also a concern about genetic testing for genes
consistent with autism. As presented previously, many individuals who have made valuable contributions to society have done so with the benefit of certain traits of autism, such as extreme focus (Grandin, 2006). The decision about whether or not to terminate a pregnancy due to the results of genetic testing for autism includes another layer of moral dilemma to be considered.

**Education and Autism**

Studies confirm that a child with autism requires 20 hours a week or more of intensive teaching by an adult in a one-on-one setting (Grandin, 2006). One of the worst things to do with a child with autism is to allow him to watch a great deal of TV. Highly repetitive methods in a highly structured program help facilitate a jump-start on language for the autistic children from ages two to five (Grandin, 2006). Hence, this is additional evidence that early diagnosis and intervention are crucial to facilitate the best future outcome for the child.

Although the evidence for early intervention is proven, the reality is that a gap between the time the parents first raise concerns about their child’s development and the start of an ASD program of approximately four years. This gap is detrimental to early intervention during a time critical period of a child’s development (“Could new changes be on the horizon for managing autism?,” 2001).

Another major concern for a child with autism is the tendency for children with emotional or developmental issues to be automatically shunted off to special education classes. As presented by Grandin:

A CDC study in Atlanta, Georgia, indicated that 40% of all children on the spectrum are only diagnosed at school and 41% of the special education students are on the autism spectrum. Unfortunately, there are severe cases of autism who do not receive services until they go to school (p. 56).
Autism in education is difficult from the standpoint of educators as well. A severe shortage of qualified teachers who can support children on the autism spectrum exists. As evidenced:

In the ‘National Assessment of IDEA Overview,’ published in July (2011) by the Institute of Education Sciences, 46% of school districts reported that they could not find qualified special education teachers to work with students with severe behavioral problems – a common characteristic of autism (McCulloch & Martin, 2011, p. 27).

So far, only two states – Virginia and California – have developed training for educators in regard to autism in the form of autism teacher competencies and trainings. Virginia developed their program with the partnership of the Virginia Autism Council. The program is voluntary. California currently requires veteran teachers and the newly hired to obtain evidenced-based autism teaching strategies through the local universities (McCulloch & Martin, 2011). Research and surveys suggest that educators desire and recommend training to work with autistic children. This willingness may contradict the common belief that teachers are already working to their limit and do not want to take on more training (McCulloch & Martin, 2011).

Public Policies Affecting Autism

With all the difficult issues surrounding raising a child with autism, it is no wonder that the public awareness of autism was brought forth as a social problem through the organization of parent groups. Parents groups increased the awareness among teachers, doctors, and the public starting back in the 1960s and that awareness has become worldwide (Wolff, 2004.) As pointed out by Schuchs-Gopaul (2011, p. 20), “Parents are their child’s best advocate and will be in that role for years.”

Historic Overview of Policies Regarding General Disabilities
Historically in the United States, public financial support regarding developmental disabilities such as mental retardation, which was what autism was once considered, fell primarily on the states to provide (Braddock, 2007). The first public mental hospital was opened in the Virginia Colony in Williamsburg in 1773 and in 1848 the first public residential school for individuals with developmental and intellectual disabilities was legislated by Massachusetts (Braddock, 2007). In addition, “more than 200 residential institutions were established by state governments between 1848 and 1970” (Braddock, 2007, p. 169).

The federal government first became interested in development and intellectual disabilities due in large part by the work of Dorothea Dix in 1854. Congress passed a bill “authorizing land grants to the states to finance state-operated residential treatment institutions for persons with mental (psychiatric) disabilities” (Braddock, 2007, p. 169). Unfortunately for the states, President Franklin Pierce vetoed it saying:

Whatever considerations dictate sympathy for this particular object, apply, in like manner, if not in the same degree, to [intellectual disability], to physical disease, to extreme destitution. If Congress may and ought to provide for even one of these objects, it may and ought to provide for them all (Braddock, 2007, p. 169).

One hundred years later, the federal government would become involved in policy-making for the benefit of individuals with development and intellectual disabilities. In 1955, Congressman John Fogarty led Congress in hearings about expanding federal programs and amending the original Social Security Act of 1935, for research, vocational rehabilitation, and income maintenance for individuals with disabilities. At total of $750,000 was appropriated by the subcommittee to the U.S. Department of Health, Education, and Welfare for neurological disorders and mental health institutes. The legislation also authorized benefits for of survivors
of individuals who qualified for Adults Disabled in Childhood (ADC) and Disability Insurance (DI) to extend past age 18 if the survivor classified as being affected by a developmental or intellectual disability (Braddock, 2007). In 1972, SSI replaced the Aid to the Permanently Totally Disabled program of 1950 (Braddock, 2007). By 2004, “1,346,222 persons with intellectual disability and related conditions including autism, Down syndrome, and congenital anomalies were receiving Supplemental Security Income (SSI)” (Braddock, 2007, p. 170).

Fewer than 10 years later, President John F. Kennedy convened a panel for study of Mental Retardation and to implement recommendations of the panel in 1962 (Braddock, 2007). John F. Kennedy was a Democrat and as such the John F. Kennedy’s Presidential Panel on mental retardation clearly expressed the ideology that people with disabilities were entitled and deserved to live and work as normally as possible. Kennedy’s Panel indicated that the federal and state governments along with the local schools and public were to be part of the initiative (Braddock, 2007).

After Kennedy, Lyndon Johnson, also a Democrat, created his Great Society legislation, which was enacted from 1964 to 1968 and developed Medicaid and educational platforms. This innovative led to Medicaid’s Intermediate Care Facility/Mentally Retarded (ICF/MR) program in 1971 and to the Medicaid Home and Community Based Services (HCBS) Waiver in 1981 (Braddock, 2007). At the peak in 1967, the number of individuals who classified as possessing intellectual disabilities and lived in state-run institutions was 194,650. The number dropped to 41,214 in 2004 with “68% of the 493,156 individuals with intellectual disabilities living in supervised out-of-home placements in settings for six or fewer persons. Twenty five years earlier, eight percent lived in such settings” (Braddock, 2007, p. 170).
In the 1950s and 1960s, discrimination and neglect of individuals with developmental and intellectual disabilities were reported in the media with great frequency. Discriminatory practices included “institutionalization without due process, denial of education, inadequate health care, abuse, and peonage” (Braddock, 2007, p. 172). Litigation was the catalyst for federal involvement. The federal government was forced into action in regard to discrimination and special education when “class action litigation high-lighted school exclusion practices early in the 1970s, and contributed to the enactment of the landmark Education for All Handicapped Children’s Act of 1975” (Braddock, 2007, p. 170). As a result:

The number of students educated in the nation’s schools with intellectual and closely related developmental disabilities (including those with mental retardation developmental delay, traumatic brain injury, and autism) grew from 223,477 students in 1958 to 1,083,993 in 2004 (Braddock, 2007, p. 170).

The legal cases also brought about the eventual funding for community service programs “from ICF/MR, Social Services Block Grant and JCBS Waiver programs and from state sources” (Braddock, 2007, p. 172). The combined power of the increasing advocacy of parents and parent groups and professional working together with legal action across the country provided the catalyst to produce funding for services (Braddock, 2007).

The federal government passed the first major anti discrimination or “rights” legislation for individuals with disabilities titled the Rehabilitation Act of 1973. The legislation carried three subsections including Individuals with Disabilities Education Improvement Act (20 USX 1400), Section 504, is the most important to parents because it provides equality for those with disabilities to obtain a better opportunities. While Section 501 and 503 covered Federal agencies of the executive branch and Federal government contractors and subcontractors respectively,
Section 504 was designed to protect people with disabilities from being excluded from any program or activity that receives Federal funding, or facilitated by the U.S. Postal Service or by any Executive agency (Center for Psychiatric Rehabilitation, 2011).

At the same time in history, parents took action against discrimination in the schools with the precedence of the civil rights movement and the Brown vs. the Board of Education decision. Parents and parent groups turned to the court system to obtain resolution and redress for the gross inequity that had been taking place in the classrooms prior to 1975. Two landmark cases were heard in two U.S. District Courts that provided the platform and structure for a state and local requirement to educate children with disabilities in the proper manner with comparable facilities and support. In the cases of;

**Pennsylvania Association for Retarded Children (PARC) v. Pennsylvania** and **Mills v. Board of Education**, the courts established the right of children with disabilities to a free, appropriate public education in the least restrictive environment by interpreting the equal protection guarantee of the 14th Amendment (The New America Foundation, 2011, p. 1)

A heavy financial burden was placed on the state and local school districts as 30 states passed laws guaranteeing the right to a free and appropriate public education for children with disabilities in the least restrictive environment. Hence in 1975, Congress stepped in to assist with funding by passing the Education for All Handicapped Children Act (IDEA) (The New America Foundation, 2011). IDEA has two main concepts: (1) parental rights to due process and (2) a permanently authorized grant program from the federal level to the state level (The New America Foundation, 2011). IDEA is a state grant program that sets certain standards for states to follow to receive funding and states may participate in the program but are not required
to do so. This is part of the challenge that faces parents with disabled children in general – the lack of uniformity between state and local resources.

**Overview of Policies Regarding Autism Specifically**

Until 1990, the challenges associated with autism were largely ignored or overlooked possibly due to the fact that the disorder was not well defined nor understood. In 1990, autism was defined as an additional category by Congress and officially added to IDEA (Yell & Katsiyannis, 2003). This was an important step in the effort to address the unique needs of parents and individuals affected by the disorder (Katsiyannis & Reid, 1999). This recognition of autism required states to provide classroom and personnel standards to developed to educate and work with children with autism. The challenge remains with the large spectrum of the disorder from low functioning to high functioning individuals. Depending upon the severity of the disorder, children may qualify under IDEA and Section 504 of the Rehabilitation Act of 1973 or may only qualify under Section 504. Section 504 of the Rehabilitation Act of 1973 does not specifically address the needs of children with autism that may provide an area for which services could be underfunded or ignored due to the financial hardship placed on the providers (Katsiyannis & Reid, 1999).

In 1994, Part C of IDEA finalized the phase in process for states providing programs for family–centered developmental services with delays to be known as Part C Early Intervention (EI) programs. The program was designed for infants and toddlers from birth to three years old who qualified with developmental delays. The program came to be in an effort by the Federal government to address;

the urgent and substantial need to minimize the developmental problems of infants and toddlers with delays; reduce future special education costs; minimize the likelihood of
institutionalization; and enhance local capacity to identify, evaluate, and provide services to infants and toddlers with developmental delays (Grant, 2005, p. 243).

Federal funding only covers general administrative costs leaving the rest of the costs to the states. “This increase in EI utilization and cost came at a time of increasing state budget deficits, which cumulatively totaled $17.5 billion in fiscal year 2003. Unlike the federal government, states are required to balance their budgets, and they have developed a variety of strategies to do so” (Grant, 2005, p. 243). “Without early diagnosis and treatment, the average cost to the state over the life of a child with autism is more than $2 million” (Saunders, 2010, p. 39). In an effort to alleviate part of the financial burden of the EI costs, states created restrictions for program eligibility, started charging fees to parents, shifted costs onto the health care system and enforced insurance collection practices. In addition, much of the funding for such programs were cut to make up for shortfalls in the budgets, thus availability of services diminished, particularly for lower income families who could not afford to pay additional fees (Grant, 2005). Poverty only exacerbates the problem of being able to access child health care services. “In 2008, the families of 13.5 million children in the United states lived below the federal poverty level ($22,025 for a family of four)” [A citation goes outside the cited information but inside the sentence--the period goes after the citation, the quotation mark before the citation] (Hernandez, Montana, & Clarke, 2010, p. 291). The dilemma is the evidence that early intervention for many childhood problems including autism can improve the trajectory for normal development for a child, thus saving future public costs but the immediate financial burden can be great. A conservative view would side with the responsibility of parents to raise their own children while the more liberal debate the responsibility of society to assist those considered deserving or vulnerable, such as someone affected by autism.
According to Jeff Sell of the Autism Society of America, “This one disorder in and of itself has the potential of bankrupting the United States health care economy” (Dusenberry, 2009, p. 26).

**Political and Cultural Overview in Regard to Children and Child Care**

The prevailing American culture during JFK’s political influence was a transitional time from the 1950s where families presented a perfect picture façade to the more open and confrontational attitudes that would escalate after his death. During the 1950s families did not should imperfections and moral and ethical codes were held to a high standard. Families would not expect to be assisted with child care in the home and would be likely uncomfortable and maybe embarrassed by the existence of a disabled child. It was the norm to institutionalize the abnormal and not to discuss such matters openly. JFK’s Presidential Panel and more liberal democratic ideology brought the issues of disability to the forefront. During the 1960 and into the 1970s, during the republican Nixon and Ford eras, in part due to the disillusioned youth and rise of the feminist movement the culture changed and became more open. More women went into the workplace (Monk, 2010). During the 1980 and the republican Regan era, double income families, inflation and mobility became more prevalent. Spending cuts also became prevalent and behavior health was a prime target for cuts (Kishi, Kathol, McAlpine, Meller, & Richards, 2006). Families became more comfortable with both parents working and the income generated. During this time, more families relocated farther from their birth families and the extended family was less of a convenient support system. Childcare became more of an issue. The dependency on outsiders to provide quality child care increased (Wolff, 2003). As more parents became concerned with similar issues, particularly pertaining to child care, the more parents banded together in groups and organized to demand social justice for deserving needs.
As more parents became affected by the stigma or enigma of autism, the demand for answers created a force for social justice specifically for help for families affected by autism. In 1990 that autism was recognized as a social problem and added to IDEA as an additional category, the democratic Clinton era of the 1990s strengthened family social policy with enactment of laws such as the Family Leave Act, the renewed priority on education, and Hilary Clinton’s suggestion that it “Takes a Village to raise a Child,” child care became an important and widespread responsibility to be shared. The boon economy and balanced budget of the Clinton era evaporated during the republican Bush years as spending rose and taxes were cut and increasing demands of parents, educators and health professionals became louder and more insistent (Burger, & Zagler, 2008). At the time of economic downturn happened while the rise of technology enabled more information sharing - true and false - about the mysteries of autism. Technology also allowed more parents and parent groups to better organize to demand help from where ever help could come from. Autism could be brought forth as a social problem more forcefully and easily with the proliferation of technology.

**Why Autism is a Social Problem**

“During the last two decades autism has moved from relative obscurity to the center of media attention and public awareness. No other child psychiatric disorder has seen such an increase in fund raising activity and lobbying for federal dollars” (Singh, Illes, Lazzeroni, & Hallmayer, 2009, p. 788). “Autism now is more common than juvenile diabetes and childhood cancer. More than 250,000 children ages 6 to 21 with autism received public special education services in 2007, compared to 54,000 in 1998” (Saunders, 2010, p. 36). The dramatic increase in diagnosed cases of autism has produced the elevation of the disorder to an urgent public health concern by the Centers of Disease Control (Saunders, 2010). The debate ensues whether the
disorder has flourished or awareness of the disorder has increased regarding the reason behind the sharp rise in number of reported cases, or both. Financial costs are reported to be approximately $3.2 million to care for an individual affected by autism over a lifetime (Saunders, 2010). Lawmakers are charged with deciding where the ultimate financial responsibility lies in regard to taking care of individuals affected by autism, whether it be the families, health insurance companies, schools, or others. A determination must also be made regarding how to spend the limited resources on which services and programs. Grassroots organizations are speaking out and holding legislators responsible such as in the case of Autism Society calling on Congress to reform Medicaid. The Autism Society suggested the use of vouchers to reduce fraud and abuse citing that Medicaid is a lifeline for those affected by autism (Autism Society, 2011). Legislation in regard to autism has increased:

Between 2006 and 2007, states passed nearly 50 bills. In 2010, 44 states and the District of Columbia considered more than 400 bills. The more than 60 autism-related bills enacted in 2010 ranged from increasing awareness to appropriating funds for services (Saunders, 2010, p. 39).

The challenge lawmakers and the public still face is the coordination of services regarding early diagnosis and intervention for autism. As the population affected by autism continues to increase, investment in early intervention may reduce the demand for more costly services in the future (Saunders, 2010). Most recently in October 2011, President Obama signed into law the Combating Autism Reauthorization Act (CARA) that renews the Combating Autism Act of 2006 for an additional three years. The combined support of the original act and the current law is nearly $2 billion for research and treatment. This legislation signals that autism is considered a national health priority (Fields, 2011).
Who is Affected by Autism

The most obvious answer as to who is affected by autism is the family of autistic children, particularly the parents. Most parents are at a loss when suspecting a diagnosis of autism for their child. Parents tend to initially panic and information is not readily available as to who to turn to for a proper diagnosis and to what services are available. It is apparent that the health professionals skilled in detecting autism and the services available vary widely depending upon the area in which the family resides (Kelderman, 2011; Dusenberry, 2009). The emotional, physical, and financial strain that autism exerts on a family is tremendous. The family tends to split with one parent attending to the needs of the neuro-typical children and the other parent tending to the autistic child (Kelderman, 2011). Siblings suffer because the majority of time and resources are necessitated for the child with autism. Parents already under normal life stresses are pushed much farther by the demands and uncertainty of raising a child with a nebulous condition as autism.

The educational and health care systems are also affected by autism. Educators and health care professionals require specialized training to properly support autistic children. This specialized training requires funding and availability of credible information and programs.

The federal, state, and local governments are affected by autism as lawmakers struggle to determine how best to funnel funding for all of the demands of constituents, particularly in times of economic hardship for the majority of the world. It is difficult to determine who is not affected by autism. Autism affects the majority of people whether directly or indirectly due to the limitation of resources and credible information. Funding shunted toward autism may mean less for someone else.

Who Benefits from Autism
It may be difficult to understand how anyone can benefit from autism. The uproar and panic of parents has opened the door for unscrupulous practitioners who prey upon the fears affected parents. Practitioners who have been discredited in one community may merely move to another area to continue to profit from the parents who desperately cling to the hope of finding the answer in touted “treatments” (Kelderman, 2011).

It is also important to remember that many highly functioning autistic individuals have used their “abilities” to make advancements for society. It is apparent those individuals benefitted from receiving the necessary support as a child (Grandin, 2006).

Solutions to the Affects of Autism

The support and funding for programs and services for those affected by autism have begun to be defined and produced. Specialized education and training has been developed and is becoming more available to the educators and health care providers who require it. Due to the advancements in knowledge and technology from the demands of parents and parent groups, more wide spread and credible information is being proliferated by organizations such as Autism Speaks and other autism-focused organizations. Research being conducted such as the study of post-mortem brain tissue of autistic individuals is starting to bridge the gap in understanding the underlying cause of autism (Singh, et al., 2009). Hopefully the some of the confusion surrounding the diagnosis of autism will be alleviated with the release of the new DSM-V in 2012. In the new DVM-V, all of the various types of autism will all be considered ASD. Asperger’s and PDDNOS will no longer be separated from autism and levels of functioning and severity of autism will be diagnosed (Kelderman, 2011).

Conclusion
Political and cultural changes have brought about changes in the view of autism and the range of intervention and treatment offered. This change in policies has also helped improve the services available for individuals with autism (Wolff, 2004). Although great progress has been made, a great deal more needs to be done to address the disparity between states and communities with regard to the resources available to parents. It is apparent that the work of parents, parent groups, and the various non-profit organizations developed to help address the issues of autism will be required to continue to push the public and government to find answers and solutions to the challenges of autism. As stated by McCulloch and Martin (2011, p. 27), “Autism is not going away. Nothing is going to change if we accept the status quo.” The social problem of autism seems to be a worthy challenge for our social workers today and for the foreseeable future.
References


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