

Autism education for caretakers: Tracing the evolution of the disorder and its impact on the education of caretakers and teachers of children with autism

Mariana Suárez-Rebling

Advised by: Fred Volkmar

Submitted to the faculty of the Department of Cognitive Science in partial fulfillment of the requirements for the degree of Bachelors of the Arts

Yale University
April 24, 2020

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

INTRODUCTION

Today, Autism Spectrum Disorder (ASD) is a commonly used term. However, this has not always been the case. Unlike other commonly known conditions, the history of autism includes many detours before arriving to diagnostic criteria and the understanding that we see today. Initially, autism was considered a form of childhood schizophrenia that was caused by parents who lacked warmth in their parenting. Following this assessment, people believed that autism was actually a set of developmental disorders, all related to one another, whose composition caused children to have a certain set of symptoms. It was not until much later that this hypothesis was debunked and views began to shift. Ultimately, autism became what it is today: a spectrum disorder with a wide range of impairments and degrees to which each child is affected.

Given the long process of understanding children's behaviors with regards to autism, the education surrounding the needs of these kids has also taken a long time to adapt. As any person working in special education can tell you, children with autism are all very different. Their needs and specialized attention are extremely individual and can only be understood through extended observation and continuous one-on-one work. Like many things, learning the needs of a child who has autism is rooted in experiments and failure until you find a way to best communicate. This becomes increasingly difficult when the child in question is non-verbal. Similarly to cases of children with developmental differences, children with autism have better chances of being high-functioning and thriving in adulthood if there is intervention early on. This requires a diagnosis to occur at an early age and for the right tools to become available to caretakers and educators in order to provide the most adequate care to the child. We will delve deeper into what

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

these tools and education look like, but, first, we must understand the background of specialized education.

THE HISTORY OF SPECIALIZED PUBLIC EDUCATION

The extent to which special education programs did not exist in the United States can be traced back all the way to 1893 when the Massachusetts Supreme Court allowed students to be expelled from public schools due to poor academic ability (*Watson v City of Cambridge*, 1893). This instigated a long list of legal precedent allowing schools to discriminate against students with disabilities.

In the 1930s, disabilities were only beginning to be widely recognized in the United States. Children who were viewed as “different” were often labelled “mentally retarded” and “stupid” (Osgood, R.L., 1997). Religious leaders qualified children with disabilities as children of Satan, which left families without a supportive community to turn to. Furthermore, this reaction from religious groups allowed parents to rid themselves of the burden of having a child with disabilities without the guilt associated to this given that they were a “child of Satan” (Disability History Exhibit, n.d.). Therefore, children who had learning disabilities were often sent to institutions resembling prisons where they would be ignored and left to die outside of “normal” society. If children remained with their families, the family as a whole would be ostracized and looked down on. These kids would rarely live past the age of twenty and the years that they did live were not typically fruitful given the lack of empathy and compassion displayed by the majority of society at the time (Disability History Exhibit, n.d.).

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

As a result of this general lack of acceptance, public schools were never forced to create programs that would best suit children with disabilities, as nobody was pushing them to integrate into society at all. In the 1960s, children with disabilities remained neglected and rejected from the public school system (The evolution of ‘autism’, 2020). Yet, slowly, family associations began advocating for the rights of children with disabilities and the Federal Government started allocating funds to assist this portion of society (Wehmeyer, M.L., 2013).

In 1965, Congress began discussing the need for additional funding in low-income communities where there was a clear disparity in funding and neglect for public education. They began passing pieces of legislature that allowed professionals and teachers to be properly trained to teach students who had “mental retardation”, as it was labelled at the time. Through the Elementary and Secondary Education Act of 1965, a program was created by the United States Department of Education in order to “distribute funding to schools and school districts with high percentages of students from low-income families” (Johnson, L., Obama, B., Rochester Schools, 2018). This was a promising start to creating a more equal distribution of education throughout social classes, however, it did not provide assistance or clear regulations for children with disabilities to be integrated into these public schools.

In 1966, Congress first addressed the problem of educating children with disabilities, or “the handicapped” through an amendment to the Elementary and Secondary Education Act of 1965 that established a grant program to “[assist] States in the initiation, expansion, and improvement of programs and projects... for the education of handicapped children” (Elementary and

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Secondary Education Act of 1965 (PDF), n.d.). Following Congress' intervention in 1966, a few children with disabilities were placed in public schools and attempted to succeed despite their lack of specialized attention (ESSA, 2019). The success rates of these students are poorly documented and varied widely depending on the severity of their disability. Most did not succeed due to a lack of understanding and tools needed to help them progress. Additionally, none of these students achieved any sort of higher education (something that remains an issue even today).

However, disabilities were becoming more widely accepted in society and people were beginning to shift their opinions (Raiti, C., 2014). By the 1970s, Congress realized that more needed to be done in order to ensure comprehensive education for all children despite any personalized educational needs. Two key landmark court decisions in particular established the States' responsibility to educate everyone, including children with disabilities. In 1971, *Pennsylvania Association for Retarded Citizens (PARC) v Commonwealth of Pennsylvania* was the first of these two cases. The Public Interest Law Center brought a lawsuit that became the first right-to-education suit in the country. Its goal was to overturn the Pennsylvania law and fight for quality education to all children despite necessary accommodations (*PARC v Commonwealth of Pennsylvania*, 1971). In 1972, *Mills v Board of Education of District of Columbia* became the second crucial case as it was a lawsuit filed in order to obtain free public education for all students with disabilities (*Mills v Board of Education of District of Columbia*, 1972). Following this, the Rehabilitation Act of 1973 guaranteed civil rights to people with disabilities and forced federally funded institutions to acquire necessary accommodations for them to access buildings, resulting in a more concrete integration into society (Home, n.d.).

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

By 1974, federal funding was greatly increased in order to allow states to adopt “a goal of providing full educational opportunities to all handicapped children”. This was viewed as a tactic to buy time while Congress did the necessary research and was able to create a new federal law, the Education for All Handicapped Children’s Act of 1975, which aimed to “assure that all children with disabilities receive a free appropriate public education emphasizing special education and related services designed to meet their unique needs” (Education for All Handicapped Children’s Act, 1975). This came after Congress realized that the 1966 amendment had placed students in regular classrooms where they were essentially waiting to be old enough to drop out.

Through this new Act of 1975, a State became eligible for funding once it “[had] in effect a policy that assures all handicapped children the right to a free appropriate public education” per 20 U.S.C 1412(1) (20 U.S. Code 1412). The plan needed to be submitted and approved by the Commissioner of Education. The Act specified that children with disabilities who were receiving no education at the time needed to be prioritized through funding (Education for All Handicapped Children’s Act, 1975). Subsequently, children receiving inadequate education would be second in line once this first group was tended to. The Act described “handicapped children” as “mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped. Seriously emotionally disturbed, orthopedically impaired, [and] other health impaired children, [and] children with specific learning disabilities” (Education for All Handicapped Children’s Act, 1975). This broad categorization attempted to fill the large gap of neglected children.

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

This Act was later renamed the Individuals with Disabilities Education Act (IDEA) in order to modify and strengthen the protection of students with disabilities. In 1997, Congress enacted IDEA to address implementation problems resulting from low expectations of these students and the continuous research that showed that students with disabilities could not thrive in a “one size fits all” model of academia (Lee, A.M.I., 2020).

IDEA was pivotal in shifting special education to a model similar to what we see today. The Act required schools to have a uniquely tailored program of studies for the needs of the “handicapped child”. A meeting was required between the local educational agency, the child’s teacher, the child’s parents or guardian, and if appropriate, the child. This was called the Individualized Education Program (IEP). They would get together annually to establish an adequate lesson plan with clear goals, the current performance level of the child, the exact educational services that would be provided to the child, the date of initiation for the project, and clear evaluation criteria for the child in order to determine, on an annual basis, whether he/she was meeting his or her educational goals and succeeding in the personalized program (Guide to the Individualized Education Program, 2019). Through IDEA, students became entitled to receive special educational services through their local school districts from ages three to eighteen or twenty-one depending on the child’s needs and the severity of their condition. All of these steps were required in order for States to be granted federal funding.

Following IDEA, a few other pieces of legislature assisted in guaranteeing continued attention to the needs of children with disabilities. Generalized Acts such as the 2001 No Child Left Behind Act became an extension of the Elementary and Secondary Education Act and

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

included students with and without disabilities (Klein, A., 2020). In 2004, the Individuals with Disabilities Education Act required a higher qualification standard and training for special education teachers and enforced the participation of children with disabilities in annual state and district testing or documented alternate assessments in an effort to register the progress made by these students and their educational trajectory (Special Education, n.d.).

Federal law and guidelines for matters related to special education funding explicitly state the “maintenance of an effort” in order to assure the continued improvement of special education services (IDEA improvement, 2004). There are also clear guidelines stating that no student is too disabled to qualify for the free, appropriate, specialized education that they have been promised (IDEA improvement, 2004). There continues to be a debate, however, about whether certain levels of severely disabled children should fall under this category. Children who are in a vegetative state or in a coma are viewed by many as no longer being useful or appropriate to educate. Yet, the law states that they are required to undergo the same process of individualized attention. Children can be deemed “incapable of learning” if they’re unable to do simple tasks such as pushing a buzzer to demonstrate they have a specific need (Too Disabled or Not Disabled Enough, 2019). Others might need to use a brain implant if their mobility is limited. Some parents believe that their child gains little from an attempted education and would benefit more from specialized physical care in these cases (Baker, A. 2014).

THE DEVELOPMENT OF THE DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (DSM) CRITERIA FOR AUTISM

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

The Diagnostic and Statistical Manual of Mental Disorders (DSM), whose fifth and latest edition was published in 2013, is a publication by the American Psychiatric Association (APA) that provides standardized criteria for the classification of mental disorders (Diagnostic and Statistical Manual of Mental Disorders, n.d.). It allows clinicians, researchers, policy makers, health insurance companies, pharmaceutical companies, psychiatric drug regulation agencies and the legal system to communicate using a common language. The first DSM was published in 1952 and was created collecting census and psychiatric hospital statistics as well as the United States Army manual. Each publication and revision have added new mental disorders and removed others in order to best mirror the current understanding of disorders as per current society and professionals (Diagnostic and Statistical Manual of Mental Disorders, n.d.). Though the DSM is the most utilized system of diagnosis for mental disorders in the United States, other countries, including those in Europe, often utilize the International Classification of Diseases (ICD) produced by the World Health Organization, which provides a more holistic assessment of health. The most recent edition of the ICD includes diagnostic criteria for mental and behavioral disorders as well.

Though the DSM is frequently utilized and praised for standardizing psychiatric diagnosis and ensuring the use of empirical evidence. However, it has also been the subject of extensive controversy and criticism due to the way in which it distinguishes behavior that qualifies as “normal” versus “related to mental illness”. This division is often arbitrary and imbedded in cultural biases fogged by the increased medicalization of illnesses.

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

When the first DSM was published in 1952, 106 mental disorders were listed (including homosexuality as a sociopathic personality disturbance). Autism was not introduced as a psychiatric condition until the second edition of the DSM published in 1968. In the DSM-II, autism was said to not affect cognition. It was described as a childhood schizophrenia that caused a certain level of detachment from reality in the part of the child (The Association, Dsm-II, 1968). An Austrian-American psychiatrist and physician, Leo Kanner, started researching autism in 1943 and spoke about it in terms of children who displayed “extreme autistic aloneness” and an “anxiously obsessive desire for the maintenance of sameness”. He found that autism was a profound emotional disturbance, which was the same perspective shared in the DSM-II. This version of the manual did not include a diagnostic process for autism, however. They left all treatments open to clinicians’ observations and interpretations so there was no standardized form of care for anyone who was diagnosed as having this form of “childhood schizophrenia” (The Association, Dsm-II, 1968).

Until the late 1960s, researchers viewed autism as the direct result of mothers who lacked warmth and affection towards their children. Bruno Bettelheim, an Austrian-born American psychologist, referred to these mothers as “refrigerator mothers”. This hypothesis was proven to be false in the late 1960s and 1970s as autism research began gaining popularity. By the time the DSM-III was published in 1980, sufficient findings had been produced to demonstrate that autism was rooted in brain development and had a biological foundation. This was the first time that autism received its individualized diagnosis. It was described in the DSM-III as a “pervasive developmental disorder” and was explicitly differentiated from schizophrenia (Webb, L.J. Dsm-III, 1981). In this third edition, there were three required criteria that were stated in order for the

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

diagnosis to fall under “autism”. The three essential features were: a lack of interest in people, severe impairments in communication, and bizarre responses to the environment. The key point was that all three of these diagnoses needed to be developed within the first thirty months of the child’s life.

This set of diagnostic requirements lasted seven years before a revised version of the DSM-III was released in 1987 and removed the thirty-month qualification. The diagnosis was also broadened to include “pervasive developmental disorder-not otherwise specified” (PDD-NOS). This revision demonstrated researchers’ initial understanding of the “spectrum” quality of autism (American Psychiatric Association, 1995). The PDD-NOS reflected a diagnosis that would be most evident in someone who fell at the mild end of the spectrum. This assessment allowed clinicians to realize that there was no single condition required and that different aspects of the assessment could appear throughout the child’s life. The revised version of the DSM-III included sixteen criteria across the three established domains and required a minimum of eight criteria to be met in order for a diagnosis to be made (American Psychiatric Association, 1995). The broader PDD-NOS assessment allowed doctors to help provide care to children who required developmental or behavioral support but didn’t meet the full requirements to qualify as having “autism”. This would permit children to inquire on a specialized educational plan to best fit their needs if they were falling behind on generalized forms of education.

Autism was first described as being a spectrum of conditions in the fourth version of the DSM, the DSM-IV, which was published in 1994 and later revised in 2000. Five distinct conditions were featured. In addition to autism and PDD-NOS, which had already been

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

introduced (American Psychiatric Press, 1997). Asperger's disorder, childhood disintegrative disorder (CDD), and Rett syndrome were included as categories of conditions that would each require different treatments due to the different problems they posed. Asperger's disorder was understood to be a mild condition within the spectrum, CDD was linked to severe developmental reversal and regressions, and Rett syndrome affected movement and communication mostly in females. The research occurring at the time hypothesized that autism was deeply rooted in genetics. Scientists believed that each category within the breakdown of the condition could ultimately be linked to a specific genetic abnormality (Spitzer, R.L., 1997).

In order to prove the preexisting hypothesis, researchers spent the 1990s attempting to identify the genes contributing to autism. The Human Genome Project- an international research project aimed at understanding the sequence of the human genome - was completed in 2003 and allowed researchers to begin comprehending the functions of genes, proteins and their impact. Scientists specializing in autism research attempted to find the list of genes that would qualify as "autism genes". Hundreds were linked to the five conditions and thus treatment research adopted a different approach. The inability to focus on a smaller number of genes for each condition led experts to qualify autism as being a broad, all-inclusive diagnosis with a range from mild to severe (Fridovich-Keil, J. L., 2020).

While this qualification of a "range" was being defined in the 2000s, a spike in autism diagnoses occurred, leading scientists to believe that there was a lack of consistency in how doctors across states were diagnosing children. Some clinicians were more comfortable using the PDD-NOS criteria rather than that of autism while others diagnosed children with autism

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

instantly. . The alarming rate of increased cases was a sign of a push by parents to be given a specific diagnosis for their child. This could be due to services available to families within different states, educational aid their child would receive given the diagnosis, or the type of insurance coverage that would become available to the family. Due to this lack of standardization, the fifth and current edition of the DSM, DSM-5, which was published in 2013, introduced autism as the “autism spectrum disorder” (American Psychiatric Association, 2017). This new diagnosis was specified to have two groups of diagnosis: “persistent impairment in reciprocal social communication and social interaction” and “restricted, repetitive patterns of behavior.” It clearly states that both groups of behaviors are present in early childhood.

Each of these broader categorizations of autism spectrum disorder has underlying behaviors that still need to be identified by the clinician in order to arrive at the diagnosis, just as in earlier versions of the DSM. Asperger’s syndrome, PDD-NOS, and autism were all eliminated from the DSM-5 but “social communication disorder” was included in order to represent children with language and social impairments. CDD and Rett syndrome were disassociated from the category of autism spectrum disorder (Pervasive Developmental Disorder, n.d.).

CRITIQUES OF THE DSM-5

Before the DSM-5 was published, many people who had been diagnosed with autism, and particularly those who had been identified as having Asperger’s syndrome, were very concerned by the newest version of the book due its potential effects on their insurance coverage and other forms of assistance. Individuals who had been diagnosed with Asperger’s syndrome

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

worried that the merging of their condition with another could leave them with a less identifiable explanation for their unique challenges. Additionally, they could be deemed to no longer qualify for the services used prior to the release of the manual. Those who had milder traits would potentially be blocked from utilizing services due to the more stringent diagnostic criteria that was introduced by the DSM-5 (Torres, L., 2019).

Moving away from using the diagnosis of “Asperger’s syndrome” was very controversial. That being said, there has been more evidence to suggest that, in the years leading up to the newest DSM, children being diagnosed with Asperger’s syndrome were mostly being diagnosed in specific clinics. In other words, where you went to be diagnosed determined the likelihood of a diagnosis for Asperger’s. This is concerning as diagnoses should ultimately be more standardized. Thus, there was a strong push for the removal of Asperger’s as an independent category in the DSM-5. Ultimately, the inclusion of Asperger’s syndrome within the umbrella of Autism Spectrum Disorder helped many people who were being turned away from services that were categorized as being only for those who were “autistic”, which did not used to apply to children with Asperger’s. However, people who had been diagnosed with Asperger’s felt that that label was a core part of their identity and that in changing their label to “Autism Spectrum Disorder”, the label became more general and did not represent their specific needs and behaviors (A Critique of DSM-5, 2013).

Seven years after the introduction of the DSM-5, research still shows no cuts in services and resources designed for people who received their diagnosis prior to the new edition. There is growing evidence that the newest criteria and diagnostic requirements exclude people with

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

milder traits, girls, and older individuals looking for a first-time diagnosis. This version of the DSM, however, aims to be the first of its kind to go online and be regularly updated to mirror the most recent information being uncovered in its field (Pickersgill, M.D., 2014).

The International Classification of Diseases (ICD), which many other countries utilize instead of the DSM, released an eleventh edition in May 2018 that introduced autism in much of the same way as the DSM-5 does. The newest edition also introduced a specific Autism Spectrum Disorder section, which it had not done before. There are, however, some important differences between the explorations of the Autism Spectrum Disorder in the DSM-5 and the ICD-11.

More specifically, there are four big differences in the DSM and ICD's approaches to Autism Spectrum Disorder. First, the ICD-11 does not require a fixed number of symptoms or conditions in order to qualify for diagnosis nor does it speak of a specific combination required. Rather, the ICD introduces different features of the spectrum and leaves the terminology open to the clinician's interpretation in order to decide whether the person being diagnosed has traits that match the description or not. Second, the ICD is structured for global use, which means that it has fewer culturally specific criteria than the DSM does. For instance, the DSM focuses on what games children choose to play. This might speak to what social aspects the child is more comfortable with and illustrates repetitive behaviors. The ICD, on the other hand, emphasizes whether the child follows or imposes strict rules while playing those games. This reflects a focus on adaptive behaviors to assess whether the child might be more flexible and recognize the rules. There are two different approaches to the observation of similar behaviors, but the ICD aims to

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

enable clinicians to identify kids with higher IQs. Third, the ICD distinguishes between autism with and without intellectual disability while the DSM makes no such distinction. Fourth, the ICD highlights the fact that older individuals and women are much more likely to mask their autistic behaviors and traits, which continues to be a problem regardless of the diagnostic method used (International Classification of Diseases, 11th Revision, 2019).

After listening to a few members of the committee that put together the DSM-5, I am certain of one thing: there is still an incredible amount of information that we don't have. The DSM-5 was mainly created by a committee of fifteen experts who all had different opinions on what diagnoses should look like and what behaviors lie under each umbrella. With little data to back any single opinion, the assessment becomes a bit of a compromise between different opinions in order to arrive at a happy medium (The DSM-5's take on autism: Five years on: Spectrum: Autism Research News, 2018).

Many criticize the DSM-5, but it also contains formative improvements compared to past versions. In the DSM-5, unlike in the DSM-IV, the possibility of having autism without intellectual challenges exists. The DSM-5 also explores autism more trans-diagnostically. It allows for the diagnosis to be perceived as having more continuous dimensions. At the end of the day, labels for diagnoses are in place for the convenience of the doctors and the patients. A label allows individuals to be assessed, to understand what services they can access, what they can be provided with, and what information they require. Clinicians use the label to decide what medication or resources get allocated to an individual. There has to be a limit to the medication administered, especially with developmental disorders, but it is difficult to know where that limit

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

is. No criteria, DSM, or label will ever be able to encompass everything and everyone's individual behaviors. Furthermore, the DSM-5 removed the age cutoff in realizing that there is no evidence to support the idea that autistic symptoms have to display themselves before a certain age to "qualify" the child to the diagnosis (The DSM-5's take on autism: Five years on: Spectrum: Autism Research News, 2018).

THE FUNDAMENTAL GAPS WITHIN CURRENT RESEARCH

There are some fundamental issues with how diagnoses, whether in the DSM or ICD, have been evaluated. Autism was discovered by the observation and assessment of mostly boys. Much of the research done to this day has been accomplished by interpreting boys' behaviors. Thus, symptoms and diagnoses are primarily catered to those boys. Key issues such as social reciprocity and communication would appear to be similar regardless of gender but there is no way of knowing whether or not observed repetitive behaviors are largely based on male stereotypes. The ICD, which was released five years after the DSM-5, has tried to address most of the issues associated with the DSM-5, including the issue of gender. However, there is little to be done unless data related to girls, women, and the general autistic adult population becomes available (International Classification of Diseases, 11th Revision, 2019).

Girls, particularly those with a high IQ, have proven to be difficult to diagnose until they reach adolescence due to their impressive ability to hide symptoms. Once they reach adolescence, social needs surpass the child's social ability and forces symptoms do become for obvious. When this type of behavior does not become apparent until adolescence, the child is

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

diagnosed significantly later and can't begin receiving the necessary support. This makes it harder for there to be information and research related to girls, which in turn perpetuates the inability to adapt the criteria for them and personalize their assistance. Adults who don't receive a first diagnosis until adulthood are similarly good at hiding their symptoms, especially repetitive behaviors, which also makes it hard to diagnose and help them (The DSM-5's take on autism, 2019).

Another age group that we currently lack information about is babies. Numerous studies show the benefits of early intervention. In essence, the earlier, the better in terms of the child's chances of becoming a more independent adult. However, given the amount of information currently available to us, babies who have a genetic predisposition to autism display a lot of the same behavioral traits as infants who are not genetically predisposed but who are taking longer to reach milestones. Due to these behavioral similarities, clinicians typically wait until the child is closer to three years old in order to assess what differences remain and obtain more information to inform the diagnosis. Parents tend to notice the delays in their child's development before an assessment can be made. Once parents begin to feel worried, there is nothing the doctors can do until the stunt in development is more pronounced. This potentially wastes two to three years' worth of time when caregivers could be trying to assist and enable the development of their child. Early screening would advance ASD research tremendously, but we don't currently have the necessary findings to enable this to happen (The evolution of 'autism' as a diagnosis, 2020).

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

In addition to the current barriers for earlier diagnosis, regular diagnoses are also suffering due to clinicians' discomfort with comorbidity. During assessment, if a clinician finds that a child has Autism Spectrum Disorder, he or she will likely stop the diagnostic test rather than further exploring other conditions that might be present. However, children are constantly being diagnosed with ASD and only treated for "autism" as a blanket label when in reality they have other underlying conditions that require tailored treatment. For many years, anxiety was understood to be a function of ASD. In the past seven years, many papers have been published on the propensity for children with autism to develop severe anxiety as a separate condition that requires additional and specialized attention.

This occurs with a myriad of disorders and becomes a more serious issue when children don't get co-diagnosed with ASD and intellectual disabilities despite contradicting data. Clinicians may be uncomfortable with the topic of intellectual disability, especially when discussing it with parents, and don't mention it until the child is older and it becomes obvious. This can present many obstacles for caretakers who remain underprepared and uninformed due to their lack of knowledge on their child's condition. This is why experts are pushing for a shift in clinicians' mentality. Rather than treating the child for the umbrella term that he or she is being diagnosed with, experts are pushing for each symptom to be tackled as a unique assessment in order to provide the holistic treatment best suited for the child (Too Disabled or Not Disabled Enough, 2019).

Of course, assessing children for other conditions once Autism Spectrum Disorder has been diagnosed is associated with additional obstacles. Would the same assessment tests for

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

different disorders be equally effective for someone who is on the spectrum? Does there need to be specialized evaluations for these people? Furthermore, are the current tests, such as the Standardized Adaptive Behavior Assessment test, effective despite being based on teachers and parents self-reporting their observations of the child? Two problems that come up frequently are, 1) the person reporting doesn't realize how much they do for the child or 2) they are overly optimistic about the child's functionality. With all of these unanswered questions, education for caretakers and educators of children with autism becomes increasingly complicated.

WHAT DOES THIS MEAN FOR CARETAKERS AND EDUCATORS?

Throughout the past seventy years, the education for caretakers and educators of children with special needs has dramatically improved in the sense that an educational program now exists. Following the establishment of education- both for the child and for the people caring for the child- its actual content has not been drastically changed. The first thing that any caretaker or educator of a child on the spectrum will learn is that no two children with ASD look or act the same. Therefore, their needs will be different and unique. The best way to know what they need will be to spend time with the child and observe their trends in behavior as well as the tools they respond to the most.

The aspect of Autism Spectrum Disorder that is best understood, as Leo Kanner put it in 1943, is that children diagnosed with the disorder have an "anxiously obsessive desire for the maintenance of sameness". That aspect of the disorder is probably one of the few that has remained true and been strengthened over time. This allows experts to ensure parents and

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

educators focus on providing structure and safety to the child. Maintaining a schedule is always important although the extent to which that schedule is strict varies from one child to the next.

Nonverbal cues, especially when the child is younger are very important. This continues to be important for the many children with ASD who never develop spoken language but learn to rely on sign language. Paying attention to sensory sensitivity in the child and trying to link the tantrums and behaviors to fundamental motivations is also essential when starting to piece together the child's needs. This will often make parents feel overwhelmed and lost as they look to the child for clues needed to assemble the puzzle that is every individual (Special education in the United States, 2020).

The increasingly common trend is to place an increase in responsibility on the parent while also providing them with added support. Parents are told to become experts on Autism Spectrum Disorder. They are told to be advocates for their child, to become leaders in the communities that the child resides in and educate others on how to best approach their child so that he or she can thrive in any given environment. Parents become the voices of the child, especially if he or she is non-verbal. If the child affected has siblings, this is an added dimension that parents need help navigating. The sibling might not understand what is happening or how certain things might affect their brother or sister. The sibling might begin to feel resentful or jealous of the added attention that the child needs. This could lead to frustration or "acting out" as a way of expressing themselves. Parents are told to explain autism to their other children and facilitate the formation of meaningful relationships between the siblings by teaching them how to best communicate and play together.

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Parents are undoubtedly the subjects of immense pressure, stress, and work as fundamental tools in their child's success. However, there are now more resources available for other members of the family. Parent and sibling support groups and counseling opportunities are much easier to find than they were years ago. The first few years of the diagnosis in particular can be extremely taxing and parents report feeling exhausted at all times. This can be overwhelming and intense but the effort that is put in, especially in the early years, is crucial for the potential happiness and success of the child and family. In fact, the vast majority of resources and educational materials available to families of children with ASD are provided by and written by other parents of children who have ASD in an effort to share knowledge and foster wellbeing.

Our better understanding of the Disorder has led to an increase in diagnoses labeled as "ASD" in the past ten years. This does not necessarily mean that there are more children developing ASD but rather that the traits and behaviors are better understood and easier to label. This, in turn, has meant that the number of people who are struggling to figure out the best ways to serve their child is growing. Along with this growing number of individuals comes a growing community that can work together and support others. With so many people working to better understand the Disorder through the lens of parenting, there is a much more rapid evolution of best practices and tips to assist people who are new members to the community.

With the increase in the number of children affected, the likelihood that one child's symptoms are similar to those in other families becomes higher. Even if the particular assortment or combination of symptoms does not directly match that of another child, the individual symptoms can often be found across groups of families. This not only provides families solace in

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

what can be a very isolating disorder, but also it helps experts to identify constant symptoms among children who otherwise have different combinations of behaviors. Parents become essential to any research as observation of affected children is paramount to understanding the disorder as well as being the main form of education. As a result, many parents become researchers or increase their involvement in special education due to their pre-existing understanding and unique experience with the topic. Parents are crucial resources for the development of ASD research.

For educators, the law states a need for individualized study programs as children will presents their own set of traits and behaviors that need to be addressed differently. Unlike the education available to parents, teachers are trained special education instructors. The shortage of teachers across the United States is increasingly prominent among those focusing on students with disabilities. Due to the emotionally taxing aspect of the work, the Attrition Rate (burnout rate) among special education teachers is particularly high. In 2006, the Data Accountability Center found that more than 5.5 million children between six and seventeen years old were receiving special education services in the United States (Data Accountability Center, 2007). This means that over 400,000 special education teachers were needed in order to meet the students' needs (Data Accountability Center, 2006). An estimated 10% of public school teachers were special education professionals. However, in 2006, data showed that 50% of special education teachers left their jobs within five years (Dage, 2006). Furthermore, it was found that half of those who kept working after the five-year mark would leave within ten years. This translates to a turnover rate of 75% every ten years for special education teachers (Dage, 2006).

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Although this is concerning in any field, the data becomes all the more concerning when the children being affected are those who need structure and routine the most. In 2019, a project led by Education Week on the shortage in special educators showed a 17% drop in the number of special education teachers over the past ten years even though the number of students with disabilities between the ages of six and twenty-one dropped 1% in the same time frame (Samuels, C. A., & Harwin, A., 2020). The overall number of teachers in the country has increased over the same decade, which has helped to decrease the shortage of teachers (though it remains a problem), but incoming teachers are unwilling to specialize in students with disabilities (Samuels, C. A., & Harwin, A., 2020). In the 2015-2016 academic year, the student to teacher ratio for students with disabilities was at 1 to 17, which is lower than that of students overall at 1 to 16 (Riser-Kositsky, M., 2019). This is also a problem given the nature of special education and the need for individualized attention, which becomes difficult if one teacher has to provide seventeen unique curricula.

The nature of special education is extremely stressful as it requires high levels of energy and more engagement on the part of the educator. They have to be prepared to deal with tantrums and challenges that are not often seen in other people. This is particularly true of teachers who specialize in children with emotional or behavioral disorders such as Autism Spectrum Disorder (Wisniewski & Gargiulo, 1997). The constant need for adapted teaching and innovative approaches to education in order for students to comprehend concept or simply pay attention is exhausting everyday work. Due to the shortage that has been present over the past two decades or more, 10% of the currently employed special education teachers are not fully certified (Data

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Accountability Center, 2006). 47 states currently employ uncertified special education teachers (Data Accountability Center, 2006).

This is a big problem facing special education but not one that can be easily fixed due to the lack of available funding for educators and particularly special education professionals. Special educators typically have low job satisfaction rates, low self-efficacy, and very high stress and burnout rates (Boe, Cook, Bobbit, & Weber, 1995). The biggest problem currently facing educators is the rate of attrition. Until we find a way to better care for special educators and prevent the rapid emotional exhaustion that is inherent to their profession, the shortage will continue to grow. Personalized special education, which the law mandates, will no longer be feasible for all of the students who urgently require it.

CONCLUSION

The road to understanding Autism Spectrum Disorder is still very long. Given the resources available to clinicians, in particular the DSM, it is clear that experts did not begin to understand the structure of the Disorder and more accurately assess it until 2013. The autism spectrum is a key component to the Disorder and is a realization that led to greater understanding of the differences in severity among affected children. Currently, the problem that researchers continue to struggle with is the lack of data for specific demographics. We need to find a way to better assess infants in order to develop tactics for earlier intervention. We need more girl and women-specific data and research. We need to identify methods to run studies on girls that make it difficult for them to hide their symptoms. If girls aren't receiving help until they reach

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

adolescence, this puts them at a disadvantage that we should work to avoid. Finally, we need more data on adults receiving first-time diagnoses, as this is another demographic that does not allow for easy assessment.

Given how variable autism can be and how many different shapes and sizes it comes in, we need to shift the approach to treatment to address specific problems as opposed to treating “autism” more broadly. Sometimes comorbidities are needed in order to gather a holistic view of the child’s needs and the necessary support. Helpful resources are continuing to be born and evolve. There will always be those who criticize what is not being done, but there will also always be a need for a cut-off of for children who qualify for certain forms of aide. Where that cut-off should be will continue to be a source of debate and discussion. What assessments should be weighed more than others? Should sensory anomalies, organizational problems, or executive function be taken more heavily into account? Should the evaluation formats currently available be restructured in order to base themselves less on self-reporting done by those who work closely with the child? Should there be new ways to evaluate children for comorbidities once they have been diagnosed with ASD? These guidelines and questions will allow for an increasingly standardized form of diagnosis.

There are large variations in numbers being reported by different countries. The United States shows significant fluctuations in numbers among states, clinics, and circumstances as diagnoses are being determined by the clinics children attend to be evaluated. This is also the case internationally. In the United Kingdom, 90% of the children with autism that are receiving educational support do not have intellectual disabilities, according to the Department of

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Education (SEND). A statistic like this leads many to question the methods of data collection and accuracy of intellectual disability assessment. Due to the variety of data points that seem unlikely to work together, researchers struggle to interpret data available as it becomes increasingly complicated to make concrete conclusions from it. This is only made worse by the fact that most children affected by the Disorder cannot advocate for themselves. As parents and teachers act as spokespeople, data relies on the assessments made by those who observe the child most.

Parents and teachers can only know as much as the science and experts tell them. Their main forms of education are their own experiences with their child and those of other families affected by the Disorder. Yet, researchers and parents inevitably co-educate one another. Without the research, parents can't learn about their child's needs or become experts in the field to the degree that is necessary for their child to thrive. However, given the countless evaluations that rely on parents sharing their observations and self-reporting on behalf of the child, researchers can only collect data with the help of parents and educators. A 45-minute session between a doctor and a child will rarely be enough to correctly diagnose a child unless all of the right questions are asked. Parents won't necessarily share information that they view as irrelevant but could nevertheless unlock a myriad of other particular behaviors. In order for there to be an increase in fundamental knowledge on ASD, parents, teachers and researchers will need to work together to continue building an open source database for others.

Ultimately, everyone's goal is to work with children who have Autism Spectrum Disorder and assist them in functioning better and leading fulfilling lives. "Better" may be defined differently, but it remains the main goal. Where do we assess that "impairment" begins

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

and where help is appropriate? Sometimes children who are not properly diagnosed or are not impaired “enough” end up receiving little to no help and falling behind their peers who might have started off requiring more attention but ultimately received the assistance they required. The aim is to help children with ASD to be more independent, happier, allow them to do more, and enable them to find a place in this world. All of these categories are unique and growth is incomparable from one child to the next. This demonstrates the absolute need for the individualized education currently required by the Board of Education and the law. However, such personalized attention will become increasingly difficult if we do not find a way to retain and assist special education specialists.

There are many unanswered questions and many clear routes forward in terms of furthering research. We lack a lot of information and data, which will continue to be discovered in the next decade. However, we are in the best place autism research has ever been. Thus, children with ASD today are much more likely to live a fruitful and productive life than ever before.

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Acknowledgements

I would like to express my gratitude to Professor Fred Volkmar for his endless knowledge on all things related to children with Autism Spectrum Disorder. Taking Autism and Related Disorders and attending the Benhaven School while working on my thesis was the most rewarding academic experience I had during my time at Yale. I would like to thank Samantha Barone for allowing me to shadow her class at Benhaven weekly and giving me the incredible experience of working with her students. I would also like to thank Daniela Suárez-Rebling, my sister, who put up with my endless edits and calls throughout the process of my research and writing and who ensured that my ideas were as clear as possible. And finally, to Natalia Córdova Sánchez who provided endless support to all of the Cognitive Science seniors this year and kept us on track to produce senior projects that we could be proud of, I would like to express my endless appreciation.

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

REFERENCES

- (n.d.). Retrieved from <https://www.wrightslaw.com/law/caselaw/ussupct.rowley.htm>
- (n.d.). Retrieved from <http://eateachblog.com/burnout-rate-special-education-teachers/>
- (n.d.). Retrieved from <https://www.apa.org/advocacy/education/idea/>
- 20 U.S. Code § 1412 - State eligibility. (n.d.). Retrieved from <https://www.law.cornell.edu/uscode/text/20/1412>
- A Brief History of the Disability Rights Movement. (n.d.). Retrieved from <https://www.adl.org/education/resources/backgrounders/disability-rights-movement>
- Archer, D. N., & Marsico, R. (2017). *Special education law and practice: cases and materials*. Durham, NC: Carolina Academic Press.
- Ashby, C. M. (2011). *No child left behind act: education actions needed to improve implementation and evaluation of supplemental educational Services*. Place of publication not identified: BiblioGov.
- Baker, A. (2014, July 28). Balancing Special-Education Needs With Rising Costs. Retrieved from <https://www.nytimes.com/2014/07/28/nyregion/28specialed.html>
- Brown, J. (2019, March 13). What Really Causes Special Education Teachers to Burn Out? Retrieved from <https://www.edweek.org/ew/articles/2019/03/13/what-really-causes-special-education-teachers-to.html>
- Bruno Bettelheim. (2020, April 23). Retrieved from https://en.wikipedia.org/wiki/Bruno_Bettelheim
- Cherry, K. (2019, July 14). How Mental Health Professionals Use the DSM Today. Retrieved from <https://www.verywellmind.com/the-diagnostic-and-statistical-manual-dsm-2795758>
- Crockett, J. B. (2004). The Science of Schooling for Students with Learning Disabilities. *Learning About Learning Disabilities*, 449–484. doi: 10.1016/b978-012762533-1/50016-0

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Diagnostic and Statistical Manual of Mental Disorders. (n.d.). Retrieved from <https://www.sciencedirect.com/topics/medicine-and-dentistry/diagnostic-and-statistical-manual-of-mental-disorders>

Diagnostic and Statistical Manual of Mental Disorders. (2020, March 9). Retrieved from https://en.wikipedia.org/wiki/Diagnostic_and_Statistical_Manual_of_Mental_Disorders

Diagnostic and Statistical Manual of Mental Disorders (DSM–5). (n.d.). Retrieved from <https://www.psychiatry.org/psychiatrists/practice/dsm>

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). (n.d.). Retrieved from <https://allpsych.com/disorders/dsm/>

Disabilities in children: detection, prevention, habilitation: proceedings. (1980). Cavite.

Disability History Exhibit. (n.d.). Retrieved from http://dhss.alaska.gov/gcdse/Pages/history/html_content_main.aspx

Education For All Handicapped Children Act (1975 - S. 6). (n.d.). Retrieved from <https://www.govtrack.us/congress/bills/94/s6>

Elementary and Secondary Education Act of 1965 (PDF). (n.d.). Retrieved from <https://www2.ed.gov/about/offices/list/oii/nonpublic/eseareauth.pdf>

Forte, J. (2018, February 28). History of Special Education: Important Landmark Cases. Retrieved from <http://www.fortelawgroup.com/history-special-education-important-landmark-cases/>

Grohol, J. M. (2020, January 27). Mental Disorders & Conditions - DSM5. Retrieved from <https://psychcentral.com/disorders/>

Guide to the Individualized Education Program. (2019, August 30). Retrieved from <https://www2.ed.gov/parents/needs/speced/iepguide/index.html>

Hauerwas, S. (1986). *Suffering presence: theological reflections on medicine, the mentally handicapped, and the church.* Notre Dame, IN: University of Notre Dame Press.

Home. (n.d.). Retrieved from <https://www.access-board.gov/the-board/laws/rehabilitation-act-of-1973>

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

- Hughes, M. T., & Talbott, E. (2017). *The Wiley handbook of diversity in special education*. Chichester, West Sussex: John Wiley & Sons Ltd.
- U.S. G.P.O. (2002). *Implementation of the No Child Left Behind Act: hearing before the Committee on Health, Education, Labor and Pensions, United States Senate, One Hundred Seventh Congress, second session on examining the implementation of the Elementary and Secondary Education Act, focusing on accountability for results, parent and student choice, flexibility for states, school districts, and progress to date, April 23, 2002*. Washington.
- Oregon Dept. of Education, Special Education and Special Schools Division. (1979). *Individualized education program*. Salem, Or.
- Oklahoma State Dept. of Education, Federal/Special Services Division, Special Education Section. (2002). *Individualized education program*. Oklahoma City.
- Office of Special Education, Oregon Dept. of Education. (1992). *Individualized education program: a special education technical assistance document*. Salem, Or.
- Individuals with Disabilities Education Act. (2020, February 28). Retrieved from https://en.wikipedia.org/wiki/Individuals_with_Disabilities_Education_Act
- Johnson, L., Obama, B., Thorner, Thorner, N. J., Josey, Josey, ... Rochester Schools. (2018, April 29). Elementary and Secondary Education Act of 1965. Retrieved from <https://socialwelfare.library.vcu.edu/programs/education/elementary-and-secondary-education-act-of-1965/>
- Khaliq, U. (2018). *International human rights law documents*. Cambridge: Cambridge University Press.
- Klein, A. (2020, April 2). No Child Left Behind Overview: Definitions, Requirements, Criticisms, and More. Retrieved from <https://www.edweek.org/ew/section/multimedia/no-child-left-behind-overview-definition-summary.html>
- New York State School Boards Association. (2003). *Leaving no child behind in New York: a school board members guide to implementing the No Child Left Behind Act*. Latham, NY.
- Lee, A. M. I. (2020, April 17). Individuals With Disabilities Education Act (IDEA): What You Need to Know. Retrieved from <https://www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/individuals-with-disabilities-education-act-idea-what-you-need-to-know>

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

- Llekwellyn, A. (2008). The Abuse of Children with Physical Disabilities in Mainstream Schooling. *Developmental Medicine & Child Neurology*, 37(8), 740–743. doi: 10.1111/j.1469-8749.1995.tb15020.x
- McIntyre, E. (2016, February 4). An individualized approach to training special ed teachers. Retrieved from <https://www.educationdive.com/news/an-individualized-approach-to-training-special-ed-teachers/413180/>
- Mills v. Board of Education DC - School Psychologist Resources. (n.d.). Retrieved from <https://sites.google.com/site/schoolpsychquickreference/legal-briefs/mills-v-board-of-education-dc>
- Mills v. Board of Education of District of Columbia. (2019, November 18). Retrieved from https://en.wikipedia.org/wiki/Mills_v._Board_of_Education_of_District_of_Columbia
- Mills v. Board of Education of the District of Columbia. (n.d.). Retrieved from <https://www.usedulaw.com/438-mills-v-board-of-education-of-the-district-of-columbia.html>
- Nehring, W. M., & Siperstein, G. N. (1999). *A history of nursing in the field of mental retardation and developmental disabilities*. Washington, DC: AAMR (American Association on Mental Retardation).
- Osgood, R. L. (1997). *Becoming a Special Educator Specialized Professional Training for Teachers of Children with Disabilities in Boston, 1870-1930*. Place of publication not identified: Distributed by ERIC Clearinghouse.
- Osgood, R. L. (2008). *The history of special education: a struggle for equality in American public schools*. Westport, CT: Praeger.
- PARC v. Commonwealth of Pennsylvania: Civil Rights Litigation Clearinghouse. (n.d.). Retrieved from <https://www.clearinghouse.net/detail.php?id=11082>
- PARC v. Pennsylvania: Changing Childrens Lives and ... (n.d.). Retrieved from <http://www.studentslawyer.com/law/learn-about-the-first-right-to-education-case-that-helped-lead-to-the-idea>
- Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania: The Public Interest Law Center. (n.d.). Retrieved from <https://www.pubintl.org/cases-and->

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

projects/pennsylvania-association-for-retarded-citizens-parc-v-commonwealth-of-pennsylvania/

Raiti, C. (2014, May 4). Evolution of Autism in Public Schooling. Retrieved from <https://commons.trincoll.edu/edreform/2014/04/evolution-of-autism-in-public-schooling/>

Riser-Kositsky, M. (2019, December 19). Special Education: Definition, Statistics, and Trends. Retrieved from <https://www.edweek.org/ew/issues/special-populations/index.html>

Rotatori, A. F., Obiakor, F. E., & Bakken, J. P. (2011). *History of special education*. Bingley, UK: Emerald.

Samuels, C. A., & Harwin, A. (2020, April 23). Shortage of Special Educators Adds to Classroom Pressures. Retrieved from <https://www.edweek.org/ew/articles/2018/12/05/shortage-of-special-educators-adds-to-classroom.html>

Special Education. (n.d.). Retrieved from <http://www.p12.nysed.gov/specialed/idea/>

Special education in the United States. (2020, April 10). Retrieved from https://en.wikipedia.org/wiki/Special_education_in_the_United_States#cite_note-Esteves_and_Rao_1-1

Special educational needs and disability (SEND). (n.d.). Retrieved from <https://www.gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities>

Table of Contents- Every Student Succeeds Act (ESSA). (2019, March 20). Retrieved from <https://www2.ed.gov/policy/elsec/leg/essa/legislation/index.html>

The evolution of 'autism' as a diagnosis, explained. (2020, April 2). Retrieved from <https://www.spectrumnews.org/news/evolution-autism-diagnosis-explained/>

Ohio Dept. of Education. (1995). *The Individualized Education Program: a road map to success*. Columbus, OH.

U.S. Dept. of HEW, Office of Education. (1977). *The individualized education program: key to an appropriate education for the handicapped child; Annual Report*. Washington, D.C.

The Right to Education. (n.d.). Retrieved from <https://disabilityjustice.org/right-to-education/>

Too Disabled or Not Disabled Enough? (2019, June 12). Retrieved from <https://dredf.org/news/publications/too-disabled-or-not-disabled-enough/>

Autism education for caretakers: Tracing the evolution of education for caretakers and teachers of children with autism over time.

Wehmeyer, M. L. (2013). *The story of intellectual disability: an evolution of meaning, understanding, and public perception*. Baltimore: Brookes Publishing Co.

Wenger, S. (2008). *Education: No Child Left Behind Act*. Topeka, Kan.: Kansas Legislative Research Department.

Winzer, M. A. (2014). *The History of Special Education From Isolation to Integration*. Washington: Gallaudet University Press.