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Autism Resources in Rural America

Amanda Long

Murray State University, areynolds9@murraystate.edu

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Autism Resources in Rural America

**By
Amanda Long**

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Requirements for the
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Abstract

The topic of this final project centers around the lack of services that are available to autistic children and adults in rural America and the steps that should be taken that ensure services are available as the growing population of children grow older and need full-time care. Our modern society as well as the current healthcare system are not prepared for the growing need of an ageing disabled population. Will these disabled children and young adults flood the current long-term care facilities that are already established? Will the already stretched thin Medicare and Medicaid system cover the costs associated with the permanent placement of the growing population? This project will also fully explain and compare the seemingly endless options that are in more urban areas that may or may not have years long waiting lists. This project will also provide an overview of the definitions of autism and the challenges that can present itself with a diagnosis and the overwhelming need for early intervention which is becoming increasingly difficult to obtain with the growing numbers of diagnosis. The present number of children diagnosed in the 2023 with the same age groups 30 years ago will be compared to highlight the growing number of children and adults being diagnosed with the life altering diagnosis. Many practitioners in a clinic setting are getting limited training on the treatment of autistic patients in the formal education and are ill-equipped to deal with challenging patients, this is even more so attributed to children and adults with an autism diagnosis. After the final project the reader should have a better understanding of the challenges facing the healthcare system relating to autism.

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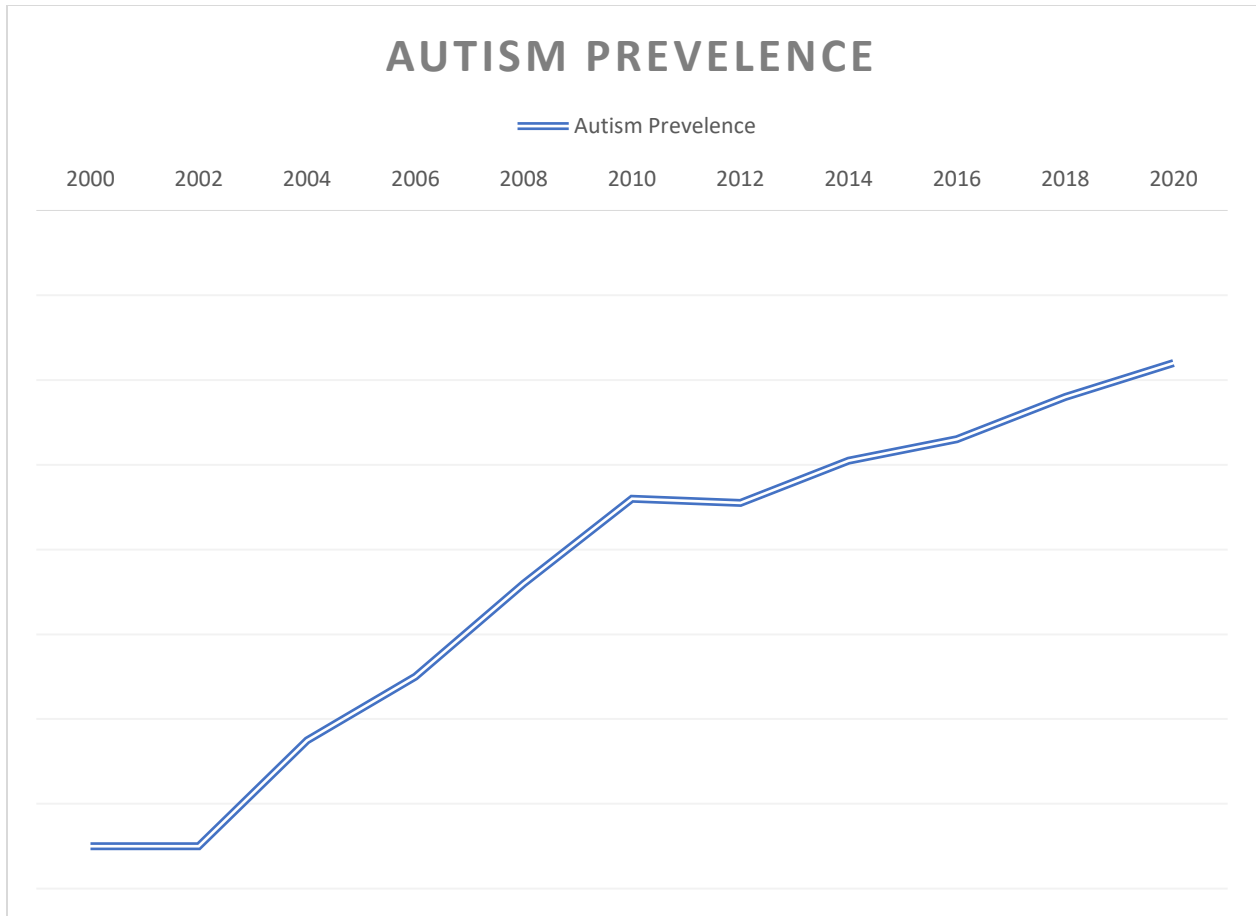
Definitions

Autism is defined as the host of complex neurodevelopment disorders that begin in early childhood and continue to affect daily functioning throughout the person's life (Rossi, 2022). Almost three quarters of children with autism spectrum disorder (ASD) suffer from other neurological conditions called co-morbidities. Some of the most frequently occurring co-morbidities are attention deficit hyperactivity disorder (ADHD), anxiety, bipolar disorder, gastrointestinal disturbances, epilepsy, fragile X syndrome, gender dysphoria, mental retardation, neuroinflammatory and immune deficiencies, obsessive-compulsive disorder, schizophrenia, sensory loss, sleeping disorders, tuberous sclerosis, Tourette's syndrome, and tic disorders (Alymov, Kapitsa, & Voronina, 2021). It is also proven that males are more likely to be diagnosed with autism than females although the exact cause for this is unknown (Bargeila, Steward, & Many, 2016). There are between two-to three males, for every female diagnosed with autism in young adolescents (Bargeila, Steward, & Many, 2016). Furthermore, females must exhibit more severe symptoms of ASD to be diagnosed at similar ages of males; and teachers in the public school setting are less as likely to express concerns for the lack age-appropriate developmental milestones in females versus males (Bargeila, Steward, & Many, 2016).

There is also a controversial co-morbidity called Sensory processing disorder (SPD) also known as sensory integration dysfunction (Walls, 2007). Sensory processing disorder (SPD) can be characterized by significant impairments with modulation and integration of sensory stimuli (McMahon, Anand, Morris-Jones, & Rosenthal, 2019). Starting in 1972 sensory processing disorder was first recognized by A. Jean Ayres, a UCLA psychologist and occupational therapist (Walls, 2007). Although many people with autism suffer from either overstimulation by outside

stimuli or under stimulation from outside stimuli this disorder is not currently recognized by the DSM-5 which makes funding for research as well as insurance coverage for treatment extremely hard to come by (Walls, 2007). Many children on the spectrum suffer from some form of Sensory Processing Disorder, which can turn everyday tasks such as wearing clothing or shopping in a loud shopping center seem almost impossible. Sensory overload in autistic individuals can lead to meltdowns, which can be described as the person having no control over their reactions to stimuli and can often be physical manifestations of an overloaded nervous system resulting in the person feeling like there is no way out of the situation and it manifesting in physical aggression and possibly self-injurious behavior (Bedrossian, 2015). There is also the opposite reaction from a meltdown, labeled as a shut-down which is a more internal reaction to stimuli overload, a person may seem to “space-out” and seem disconnected and generally need time to reconnect with the outside world, this can also cause physical pain and the range of functioning varies from each individual (Phung, Penner, Pirlot, & Welch, 2021).

There is no definitive physical test on the body to determine Autism, but there are small changes in structure of an autistic individual’s brain such as differences in the communication of the left and right brain hemispheres (Rossi, 2022).



(Loftus, 2023)

The national rates of Autism diagnosis affect roughly 1 in 36 children in the United States (Maenner, et al., 2023). During the past two decades, ASD prevalence estimates of children aged 8 years have increased markedly, from 6.7 (one in 150) per 1,000 in 2000 (one in 44) in 2018 (Maenner, et al., 2023). It is also worth noting that during the time autism was added to the DSM-III in 1980, it appeared to be a rare disorder with a rate of 3 in 10,000 children and even in the year 1999 the odds were higher but still rare at 7 in 10,000 children. It was also noted a marked gender difference in that males were much more likely (3-5 times) to have autism than females (Rosen, Lord, & Volkmar, 2021).

Autism comes with challenges many of which are made more difficult by geographic location. The signs of autism can vary greatly for each individual but can include deficits and

many categories such as social communication, having restricted or repetitive behaviors and interests and other characteristics that may include delayed language, movement and cognitive skills related to peers as well as hyperactivity and/or inattentiveness, and unusual eating habits (Autism Spectrum Disorder (ASD) Signs and Symptoms of Autism Spectrum Disorder, 2022). Some children on the spectrum will also become hyper focused on preferred subjects and interests as they age. Some of the most common and recognizable symptoms of autism in the early years are avoiding eye contact, the child not responding to his or her name by the age of 9 months and uses few or no gestures by 12 months (Autism Spectrum Disorder (ASD) Signs and Symptoms of Autism Spectrum Disorder, 2022). Not all children with Autism will have the same symptoms, some children will have many symptoms while others only a few. It is also of note that according to Rossi up to 20% to 30% of people living with autism develop seizure disorders although the reason isn't really understood (Rossi, 2022).

An autism diagnosis can be categorized into three functioning labels: level 1-3 (Lovering, 2022). These different levels of autism reference the level of support the individual needs, level one being the most independent and level 3 needed the most support (Lovering, 2022). A person with level one autism may have trouble understanding social conventions as well as having the appearance of disinterest in social interactions (Lovering, 2022). A person diagnosed level one autism might have therapy or coaching to enable them to navigate social nuances as well as therapy to learn self-regulation strategies (Lovering, 2022). They could also benefit from accommodations at school like extra time for tests.

The second level of severity of autism is a person that has similar characteristics as the of level one but to a greater extent. Some of the social and communication traits of a level two autism diagnosis may include: using fewer words, noticeably different speech, missing facial

expression or other non-verbal communication cues as well as not responding or walking away during conversations. (Lovering, 2022). A level two autistic person might benefit from speech therapy, occupational therapy and applied behavior analysis (ABA) therapy.

A person with autism that has been diagnosed with level three autism has substantial support needs. The person may be nonspeaking or have echolalia, which is repeating words or phrases they hear, they may also prefer solitary activities. The person may also only interact with others to meet an immediate need as lack imaginative play skills. Another term for people diagnosed under level three autism is profound autism (Kapp, 2023). Individuals with Autism Spectrum Disorder require behavioral interventions and specialty health services to improve social interactions, communication skills and daily functioning (Matin, et al., 2022). Profound autism as an administrative term to describe autistic people likely to have high support needs and scored 50 or less on a standard IQ test (Kapp, 2023).

Some autistic individuals as well as advocates for the autistic community reject functioning labels and the label of profound autism. Critics of the label profound autism argue that the use of the diagnostic criteria limits the persons potential, saying that it can lead to discrimination to use functioning levels at all. According the Diagnostic and Statistical Manual of Mental Disorders (fifth edition) or DSM-5, which was released by the American Psychiatric Association in 2013 categorized autism as a spectrum due to broad range of skills and deficits any one person (Kapp, 2023). History of the DSM started as a small booklet published in 1952 but by 1980, the third edition was printed with nearly 500 pages of specific descriptions of psychiatric disorders (Leggatt, 2022). By the time the DMS-III was released it contained almost three hundred different diagnoses, many of which seemed interchangeable (Leggatt, 2022). Many clinicians felt that they were encouraged to treat the diagnosis instead of the person,

making it seemingly easier to get reimbursement from insurance companies so a complete overhaul was in need for the most recent DSM-5 (Leggatt, 2022). Clinicians were also afraid that the overlapping diagnoses within the DSM-III would create too big a learning curve for new clinicians (Leggatt, 2022). The earlier version of the DSM would not list autism as a diagnosis but rather have an umbrella term of Pervasive Developmental disorder-not otherwise specified (PDD-NOS) (Walker, et al., 2004), but this was still not included until the DMS-III in 1980. Even in the latest version DSM-5, PDD-NOS seems to be a catchall diagnosis for children and teens who don't meet the criteria for a full autism diagnosis (Walker, et al., 2004). Although some clinicians use the term PDD-NOS for individuals with many characteristics of an Autism diagnosis, their symptoms are usually not severe enough to warrant an official diagnosis of autism (Benaron, 2009).

Another diagnosis that was added to the DSM was Rett's disorder. Rett's disorder is also commonly called Rett syndrome, and only occurs in females, it is also much rarer than ASD (Benaron, 2009). Rett's disorder is marked by a rapid decline in skills, average age of onset is six to eighteen months and occurs one case per 2,000 females and can be detected by genetic testing (Benaron, 2009).

Background

The history of the autism diagnosis can be dated back to the early year of 1846 in America (Donvan & Zucker, 2016). During that time according to John Donvan and Caren Zucker people were often labeled an "idiot" simply because the label of autism was not yet invented. Samuel Howe who was born in 1801 and had a medical degree from Harvard and also

went on to found the first school for people with intellectual disabilities; he was able to persuade the legislature to fund a school for the mentally disabled, The Massachusetts School for the Feeble-minded, subsequently named the Fernald State School and then later the Fernald Center (Donvan & Zucker, 2016). As far as can be determined by Donovan and Zucker, Samuel Howe's earliest observations of "idiot" labeled people suggest the earliest known collection of systematically observed people with probable autism in the United States. If some of the earlier subjects were in fact alive today, they would most likely fall under the category of autism. Starting in the 1960's, scholars discovered a small number of clinical descriptions in European medical literature, for more than a hundred years, of children who's described symptoms fit an autism diagnosis (Donovan & Zucker, 2016). One such account was of Hugh Blair of Borgue, who in the 1740's lived in Scotland, who was obsessed with washing his wig, Hugh lived with his mother and had many quirky habits that would have fit a diagnoses of Autism, his community came to accept his different ways and thought nothing of it when he would wear his wig backwards in public (Donovan & Zucker, 2016).

Leo Kanner was a Baltimore-based child psychiatrist that in 1943 spotted the behavioral traits that constitute autism such as a "strange use of language, a disconnectedness from human interaction and a rigid affinity for sameness" (Donvan & Zucker, 2016). Kanner was quoted as saying "I never discovered autism, it was there before." Through the early 1950's, all known cases of autism were diagnosed by Kanner himself (Donovan & Zucker, 2016). In the beginning Kanner believed that autism was "inborn" meaning the children were born with these deficits, which went against the thinking at the time in the mainstream psychiatric field that mental illness was caused by external factors (Donovan & Zucker, 2016). Kanner later stated that Autism was created by lack of parenting giving way to the phrase "refrigerator mother" which was used to

paint a portrait of cold, ineffectual mothers stunting the growth and development of their children (Sousa, 2011). While Kanner never actually used the phrase of “refrigerator mother” it was actually used by Bruno Bettelheim, who had no formal training in Psychiatry or Psychology and in fact held a doctorate in Art History and had been a lumber merchant, so in essence had no relevant training to make such assumptions that autism was in fact caused by cold, non-loving mothers is his book *The Empty Fortress*; but by Kanner’s suggestion that their parents, particularly mothers, were to blame for their children’s developmental problems and difficult behavior implied connection (Bennett, Webster, Goodall, & Rowland, 2018). Kanner said that children longed for parent approval and that the tantrums associated with autism served as an opportunity for retaliation (Donovan & Zucker, 2016). Many mothers were wondering exactly what they had done in the life of their child that could have caused such a lasting impact as to permanently harm them, where had they gone wrong (Donovan & Zucker, 2016). The New York Times ran an article on April 26, 1948, titled “Medicine: Frosted Children” and the main point of the piece was to introduce Time’s readers to the children who would rather just be left alone, they were lost in their own worlds (Donovan & Zucker, 2016). Bruno Bettelheim also suggested that there was a comparison between Autistic children and Holocaust victims in mannerisms and traits, which of course turned out to be false (Donovan & Zucker, 2016). Through the year 1950 almost all cases of autism were diagnosed by Kanner himself (Donovan & Zucker, 2016). A man by the name of Bernard Rimland would start to change the theory that mothers lack of affection caused Autism when his son was born in 1956. Rimland held a master’s degree in psychology as well as a PhD in experimental psychology from Penn State (Edelson, 2009). Rimland’s son started to exhibit classic symptoms of autism and he set out to learn anything and everything he could on the subject. Rimland soon discovered the “refrigerator mother” theory but could find

no scientific backing for said theory and soon stated in his book *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* that autism most likely was caused by underlying neurological and or biomedical basis (Edelson, 2009).

Another relatively well-known founder in the autism timeline is Hans Asperger. Hans Asperger was born in 1906 and coined the phrase “autistic psychopaths” in 1938. Asperger published a comprehensive study on the topic in 1942 in his postdoctoral thesis (Czech, 2018). The term Asperger syndrome was coined in 1981 by English psychiatrist Lorna Wing to describe a very mild form of Autism (Gillberg, 2023). Official recognition of Autism took almost 40 years; several lines of evidence became available in the 1970’s that demonstrated the validity of the diagnostic concept, clarified early misperceptions and autism, and illustrated the need for clearer approaches to its diagnosis (Rosen, Lord, & Volkmar, 2021). As a result of official recognition, autism was included for the first time in DSM-III in 1980 and has maintained a section in each subsequent edition of the manual (Rosen, Lord, & Volkmar, 2021). The autism community has learned to embrace their differences due to today’s neurodiversity movement, which argues that autism is not essentially a disability, but, rather, a variant of human brain wiring that merits respect, and even celebration (Donvan & Zucker, 2016). The first official case of autism diagnosed by Leo Kanner was in 1944 of a boy named Don Triplett or better known as “Case 1”. Interestingly, Mr. Triplett recently passed away on July 15, 2023, at the age of 89 (Pallardy, 2023) Donald was seemingly indifferent to the people around him and would become aggressive and violent if his patterns and routines were disturbed (Donovan & Zucker, 2016). Donald’s mother became his full-time caregiver due to his inability to care for himself, not even being able to feed himself at age 3 even though physically he was perfectly normal. Donald learned how to sit up and walk at a normal rate of development compared to his peers (Donovan

& Zucker, 2016). He was eventually sent to live in a facility for disabled children known as the “Preventorium” in Sanatorium Mississippi when he was 3 years old, and given his young age they made an exception to admit him even though he was much younger than the usual patients that resided at the facility, he lived there until he was 5 years old, which was much longer than most residents (Donovan & Zucker, 2016). Donald was also rejected by the local school system and was deemed uneducable, and due to there being no legal protections for children with disabilities had almost no formal education in his early years but eventually went into the public school system (McCafferty, 2013). Donald grew into a functional adult, he could drive and play golf and traveled extensively later in life, Donald is a success story in the autism narrative (McCafferty, 2013). Another well-known activist in the autism spectrum community is Temple Grandin. Temple Grandin is a female scientist that holds a doctorate degree in animal science and just so happens to have autism (Donovan & Zucker, 2016). She is a published author, and very successful in her field. She is a proponent of getting children with autism outside of their comfort zones and exposing them to new experiences (Donovan & Zucker, 2016). Temple Grandin is considered high functioning but was non-verbal until age three when she was exposed to early intervention speech therapy that was cutting edge technology for 1950’s America (Donvan & Zucker, 2016).

In the 1960’s scholars did some research into the last one hundred years in European medical literature looking for first-hand accounts of people like Donald and wondered how many more diagnoses there would be if families had the education and resources to pursue a formal diagnosis. In the period that Donald Triplett was born he would have been labeled as “defective” along with other children with disabilities such as down syndrome, epilepsy and traumatic brain injuries. During that period parents were told by medical professionals that they trusted that the

best option was to “put them away” in institutions (Donovan & Zucker, 2016). The practice of putting your child in an institution was so common it was generally recommended by the child physician in cases where the child would have life-long challenges. Even one of the most trusted names in child development, Dr. Spock was suggesting that parents put their children away as soon as possible after birth and just continue living their lives as if the child didn’t exist.

In 1919, Archie Casto’s parents put him in an institution in West Virginia, 50 years later he had lived his life institutionalized and had no formal education. What little language he had when he went into the institution was long gone, his parent had passed away. He had not grown taller than a typical third grade child and had lost all his teeth, which pulling teeth was a known response to children and adults who had a habit of biting (Donovan & Zucker, 2016). While Archie never had an official diagnosis of autism, by all medical accounts his symptoms fit the description of autism, but at that time he was labeled “idiot” and was never again evaluated. This was the fate of many disabled children throughout the 20th century and earlier (Donovan & Zucker, 2016).

As another example, in the summer of 1939 Donald was about to turn six years old, his mother approached a local school district about enrolling Donald in the public school system, at this time there were no special protections for children like Donald, true there were special education rooms within his local school but they could decide not to enroll a child for any and all reasons they saw fit (Donovan & Zucker, 2016). Donald was eventually sent to live on a farm with a different family in which he would come and spend his weekends with his family in town and spend the remaining time out on the farm, this allowed him free reign without the worry for his physical safety such as being run over by a car due to his natural inability to understand danger (Donovan & Zucker, 2016).

Since Autism was first identified in the 1940's, scientists and researchers have worked to gain an understanding of the nature of autism and the common characteristics demonstrated by autistic individuals. Unfortunately, much of the knowledge and research generated is not easily accessible to the public or has been very slowly disseminated (Bennett, Webster, Goodall, & Rowland, 2018)

There also seems to be a growing number of adults who self-diagnose. Many practitioners that can diagnosis an individual with autism have long waiting lists for children and don't really service adults that believe themselves to be on the spectrum. (Autism self-diagnosis: can you self-diagnose autism spectrum disorder?, 2023). With the large amount of time teenagers and young adults spend of social media with the almost constant bombardment of content created by autistic individuals it is very easy to confuse symptoms of anxiety, depression, trauma, ADHD, bipolar disorder, etc. as autism (Autism self-diagnosis: can you self-diagnose autism spectrum disorder?, 2023)

Current Programs

The future of the growing number of children being diagnosed is largely unknown. The current rate of diagnosis is unprecedented and the actual level of self-sufficiency for these individuals is yet to be determined. This raises the question of what are the plans for these individuals as they age? Are there enough resources to accommodate these children in their older years? While it is true that higher functioning individuals diagnosed with autism will most likely go on to live perfectly normal lives, whereas the lower functioning individuals will need lifelong care.

In the past it was the recommendation of healthcare professionals to institutionalize persons with life altering disabilities. In more recent years there has been a marked increase in nursing home patients younger than age 65, an increase from 10.6 percent to 16.2 percent (Ne'eman, Stein, & Grabowski, 2022). Placement of persons younger than age 65 in nursing homes increased between the year 2000 and 2007 (Ne'eman, Stein, & Grabowski, 2022). While most young adults with autism and intellectual disabilities can apply for Medicaid waivers such as Michelle P. in Kentucky and remain in their homes with the proper supports, and with an increase in the federal involvement in budget allocation allowing more money to be funneled into home and community based waivers to deter placement in outside facilities (Ne'eman, Stein, & Grabowski, 2022). For a person to be considered a long-term resident of a nursing home they need to be admitted for more than ninety days, which would exclude a person that only needs to use a nursing home due to a medical event or accident and rehab purposes. It is also worth noting that in the study conducted by Ne'Eman, Stein and Grabowski most long-term residents of nursing home younger than age 65 were predominately of African American and Hispanic descent (Ne'eman, Stein, & Grabowski, 2022). They also found a higher number of people that could be considered a long-term resident of a nursing home with expressive and receptive language delays which can be a common symptom of Autism (Ne'eman, Stein, & Grabowski, 2022). Possibly the most disturbing finding in the study conducted was that the nursing homes that had age groups of younger adult persons with disabilities had lower star ratings than home of a population above the age of 65, which is both interesting and disturbing finding (Ne'eman, Stein, & Grabowski, 2022). Most experts agree that early intervention and the proper school environment is essential for greater long-term outcomes for people with autism.

Each state in the United States has a version of the First Steps Early Intervention System, this paper will be focused on the Kentucky Early Intervention System (KEIS). The KEIS is a program for children from birth to three years (Kentucky Early Intervention System, 2023). The KEIS provides intervention services for young children and toddlers with developmental delays including autism, the provide things such as evaluation and assessments, transportation, respite care, assistive technology, nutrition services, physical and occupational therapy services, speech and communication services, vision and hearing services, and developmental interventions by trained professionals. The KEIS serves all Kentucky counties and services are based on the child's needs which are identified on their Individual Family Service Plan (Kentucky Early Intervention System, 2023).

The public education system was largely excluding children with disabilities up until 1975 with the passing of the Education for All Handicapped Children Act (EAHCA/EHS), which outlines the rights of children with disabilities and ensures they receive a free, appropriate, public education (FAPE) (Kaufman, et al., 2020). By 1973, some thirty federal court decision had guaranteed education for children with disabilities (Donovan & Zucker, 2016). The EAHCA/EHS legislation required that any public education system receiving federal funding must identify the unique learning needs of disabled students and create an effective Individualized Education Program (IEP) to provide “specially designed instruction” and deliver the FAPE in the least restrictive environment (LRE) (Kaufman, et al., 2020). The passing of EAHCA in 1975 brought about much discussion over what the definition of a free and appropriate education meant exactly. Congressional hearings on the EAHCA in 1975 stated that while some states already had laws that required a public education for children and teens with disabilities, other states did not (Yell & Drasgow, 2000). What exactly were the public schools

responsible for both financially and educationally? In the late 19th century, there was litigation in which parents were demanding the public school system to either reimburse funds or provide the intensive behavioral training made popular by O. Ivar Lovaas (Yell & Drasgow, 2000). The first state to pass legislation guaranteeing an ABA therapy-based program was North Carolina in 1971 (Donovan & Zucker, 2016). More states would follow in the coming years.

The Americans with Disabilities Act was signed by President George Bush on July 26, 1990, but the battle for equal rights started much earlier for people with disabilities (Mayerson, n.d.). According to Mayerson, “The ADA story began a long time ago in cities and towns throughout the United States when people with disabilities began to challenge societal barriers that excluded them from their communities, and when parents of children with disabilities began to fight against exclusion and segregation of their children”. The ADA began with local groups who advocated for the rights of people with disabilities and the establishment of the independent living movement which challenged the notion that people with disabilities needed to be institutionalized and pushed for more community inclusion (Mayerson, n.d.). The American with Disabilities act was the first of the legislation to protect this marginalized community and guarantee as normal of a life as possible. The ADA is a federal civil rights law the prohibits discrimination against people with disabilities in everyday activities (U.S. Department of Civil Rights Division, 2023).

The Individuals with Disabilities Act (IDEA) is additional legislation passed by President George Bush in October of 1990 (Reams, 1994). Previous passed legislation called the Education for All Handicapped Children Act of 1975 was replaced under the new IDEA legislation, and extended funding and research for all covered programs (Reams, 1994). Also under IDEA:

“These programs are revised and extended to support more research and Demonstration projects, better access to assistive technology, improved personnel Parent training programs, greater minority participation in all areas of special education, improved transition services, and more efficient dissemination of information, so that the educational and related needs of all infants, toddlers, children, and youth with disabilities can be better met. This amendment also includes a provision to deny States immunity from lawsuits for violations of the EHA, authorizes a new discretionary grant program for the education and related needs of children and youth with serious emotional disturbances, expands the definition of “children with disabilities” to include children with autism and children with traumatic brain injury” (Reams, 1994).

Autistic individuals that could attend higher education, there are many colleges that have transition programs available. Students with Autism find themselves in uncharted territory after completing high school in that they are suddenly expected to advocate for themselves after entering college. These students also have unique challenges to post-secondary education in the form of not only self-advocacy, but also self-regulation challenges, initiating and maintaining social relationships and the daily time management skills needed to succeed in a college atmosphere (Hotez, et al., 2018). Some of these challenges that these students are facing are likely due to most of the accommodations they received in the public school system are no longer applicable in a college setting. Western Kentucky University which is in Bowling Green Kentucky has a program called the Kelly Autism Program (KAP), this program offers students with autism a chance to experience college with added supports. The KAP program offers students private rooms, study table in which the student is paired with tutor who is usually an

graduate student and they meet four times a week, weekly mentor meetings, the opportunity for social interaction though participation is not required as well as mental health counseling and weekly advisor meetings (KAP Circle of Support, 2023).

The gold standard for treating Autism seems to be Applied Behavior Analysis (ABA). ABA therapy is a type of behavior modification that relies on both negative and positive reinforcement to ensure a desired response to stimuli and behavior (Sandoval-Norton & Shkedy, 2019). ABA is also used to increase language, communication, social skills and attention among others (Sandoval-Norton & Shkedy, 2019). ABA was invented in the early 1960's by a group of psychologists working at the University of Washington, but ABA therapy was made famous by Ole Ivar Lovaas, who not only used positive reinforcement to stop undesired behaviors, but used things such as shock therapy, and physical abuse to stop self-injurious behavior (Ozerk, VEA, EIKESETH, & OZERK, 2016). Lovaas was known to physically abuse the children in his care to stop self-injurious behavior (Donovan & Zucker, 2016). The first study that undeniably showed the benefits of ABA therapy was the "Dicky study", which appeared in the Behavior Research and Therapy journal in 1964 (Donovan & Zucker, 2016). The original recommendation of ABA therapy was for twenty to sixty hours a week of intensive interventions, and this became known as the "Lovass Model" (Donovan & Zucker, 2016). The average cost of ABA therapy in the 1960's could be as much as \$50,000 a year, which was more than half the median price of an American home (Donovan & Zucker, 2016).

While prevalence rates of Autism are increasing, treatment options are not which has been attributed to Applied Behavior Analysis being the gold standard for treatment of autism (Sandoval-Norton & Shkedy, 2019). Most studies that have been performed on the efficacy of ABA therapy are done on children with an Intelligence Quotient (IQ) of 70 or above, which

means nearly all studies exclude children with lower IQ's, or lower functioning children which consequently are the group that receives ABA for the longest duration (Sandoval-Norton & Shkedy, 2019). ABA therapy is considered highly effective in verbal children, but some 25%-50% of children with Autism never develop verbal communication. Also research has consistently found that individuals respond to the prompt in ABA therapy instead of the cues of the desired behavior which ultimately can cause prompt dependency and learned helplessness (Sandoval-Norton & Shkedy, 2019).

One area in Autism treatments that has seen significant growth is pharmacological treatments. Many new prescription drugs have been approved for the treatment of core deficits caused by autism. Some of them are anti-psychotics such as:

Sedative antipsychotics: levomepromazine, chlorpromazine, chlorprothixene, alimemazine, and periciazine

Incisive neuroleptics: haloperidol and trifluoperazine

Atypical neuroleptics: sulpiride, clozapine, risperidone, paliperidone, and aripiprazole (Alymov, Kapitsa, & Voronina, 2021)

Although these drugs listed above can be used to treat some of the core challenges that can result in autism, the side-effects can be debilitating. Some of the more common side effects of the most popular drugs are weight-gain, sedation, increased appetite and withdrawal dyskinesias when the drugs are discontinued (Malone, Maislin, Choudhury, Gifford, & Delaney, 2002).

Another popular therapy commonly used is Picture Exchange Communication System or PECS. This is the process of using a set of basic picture pieces of everyday objects and simple one-word selections that non-verbal persons can use to communicate and is commonly used with

non-verbal children diagnoses with autism (Lerna, Esposito, Conson, Russo, & Massagli, 2012). Advances in technology has also given way to using a picture communication computer program and portable electronic devices, or an augmentative and alternative communication (AAC), such as an Apple IPAD, there are many different APPS available such as Proloquo2Go and LAMP (Binger, Kent-Walsh, King, & Mansfield, 2017). Although these speech devices can be very beneficial the cost can be considerable, making it out of reach for lower income households.

Speech Language, Occupational and Physical Therapy are all options for treating core deficits of autism in children and young adults. It should also be noted that the chance of a child utilizing these above-mentioned therapies goes down the higher the age of diagnosis (Yingling & Bell, 2020).

A growing area of concern is mental health supports for people with autism. The growing number of people with autism that are experiencing anxiety and depression are 50 percent higher than in the same age group of neurotypical peers (Cooper, Smith, & Russell, 2017). Some of the contributing factors associated with this statistic can be societal stigma attached to an autism diagnosis, uncertainty in everyday situations, and fear of sensory overload.

There is also a higher risk of suicide in the autistic community versus the non-autistic community even though the exact reason is yet unknown (Pelton, et al., 2020). The suicide rate has been increasing over the last 15 years, by roughly 30 percent across the United States (South, et al., 2020). Many in the autistic community report the typical suicide risks such as depression and anxiety but also reported risk factors such as camouflaging or what is referred to as masking their autistic traits to those of a non-autistic person to fit in, and also trying to maintain and function in everyday life without the required supports necessary for a balanced life (Pelton, et al., 2020). In a typical comparison, males die by suicide at a higher rate than females, but this

balance is not present when comparing statistics of individuals with autism (South, et al., 2020). There is much speculation as to why the suicide rate in autistic individuals comparing males and females seems to be different than in the neurotypical studies, but later diagnoses and easier masking in females seems to be a factor in these statistics (South, et al., 2020). There isn't a lot of data available to study the differences in mental health needs of autistic individuals versus non-autistic populations, more funding needs to be allocated to better understand the differences in the mental health care needs of the autistic community.

Family Resources

Raising a child with autism can be extremely overwhelming for families and caregivers, they have a higher stress level, higher rates for divorce, an increase in mental and physical problems compared to parents of both neurotypical children and children with other developmental disabilities (Karst & Van Hecke, 2012). All parents have certain expectations when they have children, certain milestones they look forward to their children achieving. Having a child that is later diagnosed with a life-long disability such as Autism, seems almost insurmountable and all the dreams a person can have for their children are called in to question. Several studies have suggested that when a child is diagnosed with a chronic illness, such as a lifelong disability such as autism, parents begin an emotional process of recognizing that the expectations they had imagined for themselves in terms of becoming a parent and raising a child will now be dramatically altered, and this creates a heightened sense of uncertainty (Darnell & Scott, 2023). It has also been observed that parents of children with autism have the same stress levels as combat soldiers (Diament, 2009). A group of researchers followed group of moms with

adolescent children diagnosed with autism for eight days, and the end of each day the mothers were given a questionnaire and on four of those days measured the hormone levels to determine their stress. (Diament, 2009). The results of this research indicated that the hormone levels measured in each of the moms tested closely resembled the same tests in combat soldiers. Approximately 85% of people diagnosed with autism present with cognitive and/or adaptive limitations and will need life-long care (Karst & Van Hecke, 2012).

Families living in rural-America have reported having higher stress levels than their urban counterparts. Emotions reported in one study conducted were fatigue, exhaustion, feeling burned out, anxiety, frustration (Ault, Breitenstein, Tucker, Havercamp, & Ford, 2021). There seems to be less family support in rural settings in the United States compared to urban centers, an example is decreased peer support groups and physician led education. Many families leave a physician's office with no more knowledge than they entered with only 40% being given additional educational resources by the diagnosing physician (Scarpa, et al., 2020), and 13.3% reported they were given no additional information. Many parents find that the only information they can find is through an internet search. Rural families will not even find many books relating to autism in the local library as compared to urban libraries.

In the past parents were given only one choice for their children who had an autism diagnosis, and that was to put them in institutions as wards of the state. Many children with autism are still spending weeks or even months in hospital emergency rooms waiting for treatment (Jewett, 2017). These children find themselves with no community supports to ensure they can live independently or with members of their family. These children and adults can often have violent outbursts that many facilities are unable to manage and even go so far as restraint, sedation, and isolation to ensure the safety of staff. (Jewett, 2017). For example, a sixteen-year-

old Ben Cohen spent 304 days in the emergency department of Erie County Medical Center in Buffalo, New York where his room was “retrofitted so the staff could view him through a windowpane and pass a tray of food through a slot in a locked door” due to his aggressive and violent behavior (Jewett, 2017). Many families are finding they have no other alternatives than to call 911 when their child, no matter the age, become violent and they can no longer handle the outbursts due to the safety of not only themselves, but the child as well.

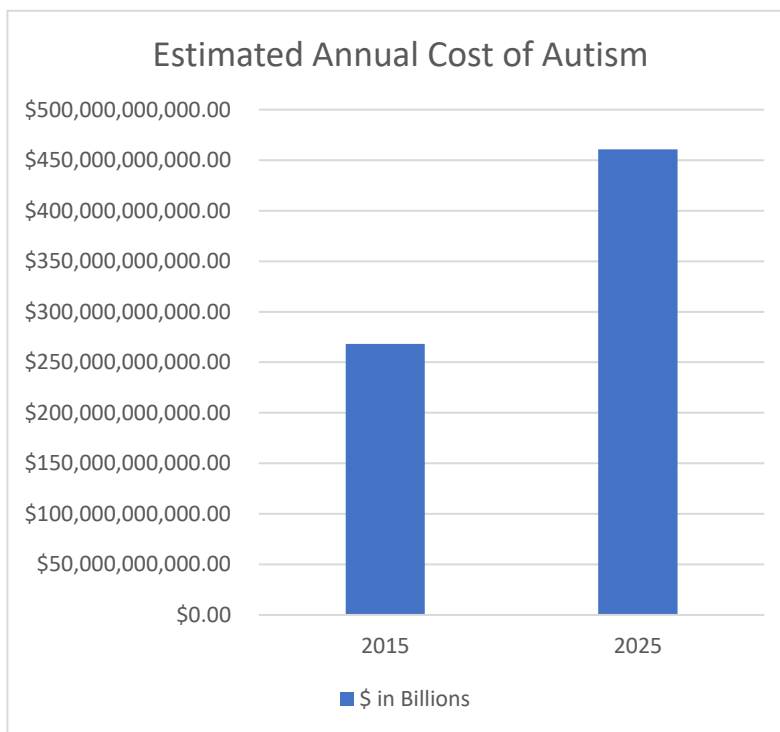
Parents of autistic children are sometimes featured in mainstream media not for the good works they perform or to be praised for facing another day due to the challenges they face, but for what is called filicide. Filicide is the murder of your own child (Palermo, 2003). Many parents and caregivers of children with not only autism but any life-long disability can feel alone and isolated. G.B. Palermo in 2002 published findings that the leading cause of child death in developed countries is murder, with most victims being victims of filicide.

Children with disabilities are more likely to be abused than children without disabilities (Edelson, 2009), they are in fact three to four times more likely to be treated violently. Reasons for this can include the children are not as aware of what is considered to be acceptable behavior, lack of communication abilities may make it harder for the child to disclose the abuse, mobility issues may make it difficult for the child to physical distance themselves from the abuser and the need for more personal care creates more opportunities for the abuse (Edelson, 2009). The families of children with disabilities can have negative feelings about having a child with a disability. The demands placed on a family caring for a disabled child places a large amount of stress of care givers who may not have proper levels of respite care (Edelson, 2009). Also, physicians and medical professionals may not take into consideration the personal needs of the patient with a disability, but instead focus on the caregiver therefore not looking for signs of

abuse in the patient (Edelson, 2009). Specifically with autism, “mothers caring for children with autism have been found to have higher levels of mental health problems” compared to parents of children with other disabilities or parents of children with no disability (Edelson, 2009).

Funding Autism Programs

The funding for many treatments for autism such as Applied Behavior Analysis, Speech and occupational as well as physical therapy can seem difficult to navigate. There is little data that examines the direct out of pocket costs families face when raising a child with autism but the societal costs of autism are exceptionally high, estimated at \$3.2 million per lifetime and an average of 14% of total household income annually (Parish, Thomas, Rose, Kilany, & Shattuck,



2012). As seen in the chart to the left, the annual cost of the care associated with a person with autism has substantially increased in recent years and is projected to increase even more by the year 2025 (Leigh & Du, 2015). Most children with autism receive services in both a clinical and school setting making it difficult to determine

cost averages (Parish, Thomas, Rose, Kilany, & Shattuck, 2012). Approximately half of children

with autism had Medicaid coverage (Parish, Thomas, Rose, Kilany, & Shattuck, 2012). Parish, Thomas, Rose, Kilany and Shattuck also published a table with their expense findings, stating that 31% of families averaged over \$1000 out-of-pocket costs within the time frame of their study from all 50 states with Kentucky ranking number 11 out of 50 in total expenditures for families.

Many states have Medicaid waivers, such as the Michelle P. waiver in the state of Kentucky. In 2002, Kentucky's Protection and Advocacy Division filed a lawsuit against the Kentucky Cabinet for Health and Human Services on behalf of a young woman named Michelle Phillips, arguing that the state was not offering adequate community-based services for persons with disabilities, after 6 years a settlement was reached in federal court which led to the creation of the Michelle P. Waiver (Darnell & Scott, 2023). The Michelle P. Waiver is both federal and state funded to the tune of 70% federal and 30% state (Darnell & Scott, 2023). Given that annual health care expenses for children with disabilities are more than three times those of neurotypical children as well as the constraints on the availability of the Michelle P. Waiver, it is plausible that parent caregivers navigating Medicaid may experience financial uncertainty (Darnell & Scott, 2023). Families raising children with autism are uniquely vulnerable because of the markedly higher levels of financial burden they incur, even compared to families raising children with other special health care needs due to typically needing not only intensive medical care, but also other expensive services such as educational services, supervision and often a range of therapies (Parish, Thomas, Rose, Kilany, & Shattuck, 2012).

Services in Rural America

Rural America covers more than 70 percent of the country (Anarde, 2019). Rural residents make up only one-fifth of the total population despite being the biggest portion of the country (Weiner, 2003).

One of the biggest problems for newly diagnosed children is the wait for services. Living in rural areas of America can make this problem even worse. It has been documented that the earlier a developmental delay in children is detected, will directly reflect the general outcome of services in early childhood. The CDC estimated that 17 percent of children have some type of developmental delay, yet less than 50 percent of these children are identified before they reach school age (Benaron, Screening for ASDs: Past, Present, and Future, 2009). A study was conducted by web research to determine the States with the most resources a diagnosis of autism and it was found that Alaska, Nevada, Wyoming, Montana, and Arizona had the greatest distances to travel in order to receive a diagnosis while West Virginia, Kentucky, Maine, Mississippi, and New Mexico had the shortest travel distances (Ning, et al., 2019). In the same study it was determined that diagnostic resources were the most underrepresented, with 83.86% of all US counties lacking diagnostic resources (Ning, et al., 2019). The average age of diagnosis in the United States is estimated to be over 4 years old, with about 27.1% of children not being diagnosed until around 8 years old (Ning, et al., 2019). A later diagnosis means lost time in Early Intervention services.

In general, rural parents reported decreased access to services, and the services themselves were less effective (Mello, Goldman, Urbano, & Hodapp, 2016). In addition to a diminished presence of and access to minimally adequate care for rural areas, there is a lack of evidence-based practices for identifying and providing services for individuals with ASD. This combination of factors contributes to a variety of unfavorable outcomes for affected children

who live in rural locations, such as delays in developmental screening and diagnoses as well as fewer available interventions which can lead to comparatively worse educational and functional outcomes (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017). Many medical professionals capable of labeling a child with an autism diagnosis are overburdened by increasing numbers of patients waiting for an assessment, this can create waitlist of more than 12 months in some cases, which can be made worse by living in a rural and remote area (Ning, et al., 2019).

For families in rural areas 63% obtained an autism diagnosis only after their third visit to a practitioner, so not only are they waiting longer for a diagnosis but also driving long distances in some cases for that diagnosis (Ning, et al., 2019). As an example, a family in Alaska might need to drive up to one hundred miles to see a medical professional capable of performing an autism evaluation as compared to New Jersey where is average travel distance is 3.74 miles (Ning, et al., 2019). Of the 3142 US counties, only 507 have one or more diagnostic resources (Ning, et al., 2019), which means that in many rural area's autism is underdiagnosed meaning later treatment. Rural areas not only have unique needs concerning healthcare, but in places like rural Appalachia which consists of the mountainous range in the eastern United States, not only is there a disparity to obtaining a diagnosis of autism, but there can also be other cultural barriers to receiving treatment. A study was conducted of the Appalachian region of southwest Virginia in which it was discovered that along with all normal barriers to medical treatment such as travel distance and lack of medical professionals, there can also be a distrust of outsiders that enter the community (Scarpa, et al., 2020). People from the surveyed region in Virginia reported factors specific to their Appalachian culture that prevented them from fully engaging in treatment (Scarpa, et al., 2020).

Rural parents also reported higher stress levels than their urban peers due to lack of support in rural settings. They also reported lower levels of quality of life than parents of children without disabilities (Ault, Breitenstein, Tucker, Havercamp, & Ford, 2021). Rural families also face more social isolation without access to support groups that can be found in more urban areas and also experience more marital strife than most parents of non-disabled peers (Ault, Breitenstein, Tucker, Havercamp, & Ford, 2021).

Rural residents with any type of disability face more obstacles to quality healthcare than their non-disabled peers including limited numbers of qualified primary care physicians and having to travel long distances to receive specialty care (Iezzoni, Killeen, & O'Day, 2006). In general, people with disabilities report lower satisfaction levels with their healthcare, compared to non-disabled persons (Iezzoni, Killeen, & O'Day, 2006), reason for this may include the complex needs of people with disabilities in relation to healthcare. According to a survey conducted by Lisa Iezzoni, Mary Killeen and Bonnie O'Day, who conducted research by interviewing people with disabilities who reside in rural areas they found that many people with disabilities must “doctor shop” to find the right physician, and this process can take years. People who were surveyed said that you interview a physician and if it is not a good fit, you go to another, and another and another until you find someone in the healthcare system that can accommodate your specific needs (Iezzoni, Killeen, & O'Day, 2006). Unfortunately, this can be a long process, and a person's health may suffer from not having a consistent physician.

Poverty has a profound impact on the lives of children, and it has been found that children from higher income families with access to private health insurance as opposed to children with Medicaid have better access to autism testing (Isaacs, 2017). In 2003, 17.6 percent

of children lived in families whose income fell below poverty guidelines (Hoynes, Page, & Stevens, 2006), which made them eligible for state Medicaid coverage.

One of the best ways to ensure a better long-term result in children with ASD is early intervention, but the average delay in initial autism screening to obtaining a diagnosis is more than two years (McMurray, 2023). In general, poor availability and implementation of mental health services for children has been reported in rural areas and the rural public education system is serving as a provider for these children that have a need for mental health services (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017). Many school's employee counselors that are trained to deal with the mental health needs all of students, but also students with autism. Unfortunately, the school resources are only available when school is in session which is generally about 170 days a year, leaving families scrambling to find resources the remainder of the year. In areas with the funding available, extended school year (ESY) is offered which extends the normal 170-day calendar year for a slightly longer 200 days (Barnard-Brak & Stevens, 2021). Services that are given during ESY can include speech therapy and life and workplace skills (Barnard-Brak & Stevens, 2021). The school district is the deciding factor in the eligibility of which students receive ESY, and which don't. Many low budget rural and urban school districts do not offer ESY to any student and there is limited federal case law on how eligibility is determined (Barnard-Brak & Stevens, 2021). What little information is available to determine eligibility resides with local education agencies (LEAs), and the student must be at substantial risk of regression in skills to qualify (Barnard-Brak & Stevens, 2021).

It has been proposed to expand the number of medical providers that can diagnose autism to include primary care physicians to meet the demand for formal diagnoses. If primary care physicians can make official autism diagnoses, it would greatly relieve some of the back log and

increase accessibility for many rural families. It has been suggested that telehealth can play a role in the future of ASD diagnoses and certain recommended therapy options, although the effectiveness of this strategy has yet to be determined (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017).

Recommended Programs and Technology

There are many new directions being taken in the research of autism spectrum disorder. They range from better diagnostic techniques to new frontiers in genetic testing. The annual U.S. Federal spending budget for autism research increased \$23 million from 2016 to 2018 (Dattaro, 2021). The Interagency Autism Coordinating Committee (IACC) is responsible for tracking autism research funding since 2008. The increase in the federal budget still falls short of the increase desired by the IACC even though it has increased 74 percent since it began tracking in 2008 (Dattaro, 2021). The annual funding goes for programs and research in areas such as risk factors, treatments and interventions, biology, screening and diagnosis, lifespan issues, services and infrastructure and surveillance (Dattaro, 2021). One area that needs improvement is lifespan issues and services, with only 10 percent in 2018 of the annual budgets as opposed to the largest portion going to research autism's biology (Dattaro, 2021).

Although there are no biological markers that can definitively test for autism spectrum disorder, the research and study of brains scans comparing a person with autism compared to a neurotypical person it was found that both subjects show similar brain activity using a reward system (McNaughton, et al., 2023), although previous studies had mixed findings. A reason previous studies had mixed findings could be associated with the rewards used, such as pushing a

button results in a picture of a smiling face or a non-interactive reward (McNaughton, et al., 2023). Also, the “neural processing of social rewards may vary by age and autism severity” (McNaughton, et al., 2023). This process of brain scans to compare the difference between the brain of an autistic person versus a non-autistic person is gaining popularity in the research field. The need to define what makes a person autistic has not changed through the years.

The future of the diagnostic process is evolving. The process of using eye-tracking for the diagnoses of people suspected of having autism is leaping to the front of available technology. The lack of objective, quantitative biomarkers has been a hindrance in the progress of developing better diagnostic procedures, eye tracking may change that (Dawson, 2023). In a study conducted on the certainty of autism diagnosis only 70.2% of 496 children surveyed were diagnosed with autism with a high level of certainty, given those numbers approximately 1 in 3 children are associated with uncertainty by the clinicians (Dawson, 2023). The idea behind using the eye tracking technique is that:

Autism is characterized by decreased spontaneous visual attention to social stimuli (social attention), a feature that is apparent early in life. The Autism biomarkers Consortium for Clinical Trials, a National Institutes of Health multisite study of 6 to 11 years old autistic and neurotypical (i.e., not displaying signs of autism) children, evaluated biomarker properties for a battery of eye-tracking tasks, including acquisition rates, construct validity, stability, and group discrimination. (Dawson, 2023)

The study conducted on eye-tracking was able to classify autism vs non-autism with 71.0% sensitivity and 80.7% specificity with a positive value of 76.2 (Dawson, 2023). The eye-tracking test is intended to help clinicians along with traditional diagnostic testing technique but raise the level of certainty of the testing practitioner. This study is not doubting the long used

diagnostic evaluations, it just hopes to aid clinicians. Some have argued that incorporating the eye tracking technology could potentially allow for earlier diagnoses and better long-term outcomes due to earlier interventions, especially among minorities and females (Dawson, 2023).

In the past research has focused on the early developmental stages in relation to autism and less on the adolescence stage, but this later stage is an opportunity for highly effective interventions in autistic people. The rapidly growing neurodiversity movement has advocated for a reframing of autism to include the distinction of other brain related disorders (Cherewick, 2023). A promising research opportunity called “Autism BrainNet” is using donated cadaver organs, specifically the brain, of autistic individuals to compare the physical brain for irregularities or similarities outside the realm of “normal” to give a physical characteristic that can be identified through the inspection of the brain of an autistic individual (Anderson, et al., 2021). Magnetic resonance imaging shows a difference in structure of a person’s brain, it lacks the definition needed to make an in-depth analysis (Anderson, et al., 2021). Substantial research about the autistic brain were first published in the mid 1980’s, but lack of available brain specimens has limited research in this area (Anderson, et al., 2021). Autism BrainNet was first drafted in 2009 and proposed a network model for “optimal acquisition, preparation, and distribution or postmortem brain to support autism research” (Anderson, et al., 2021). This model was made of a series of university-based collection sites around the country and would contribute to a general “pool” to be used by the autism research community (Anderson, et al., 2021). The rationale behind using local universities for a donation site was that local families may be more inclined to donate a loved ones’ brain if they were familiar with the facility. Autism Brain Net is also a substantial collaboration of Medical Examiners and Pathologists used during autopsy services.

Another area of Autism research that is becoming increasingly popular is alternative medicine. Alternative medicine varies greatly and can include sleep aides such as melatonin, which was reported to be well-tolerated, another option is Omega-3 fatty acids specifically for hyperactivity and were also well tolerated (Shuai, et al., 2020). Also, vitamin D supplementation was found by studies to have a significant impact on ASD children with improvement being more pronounced in children younger than 3 years old (Shuai, et al., 2020). Acupuncture has been used for over 4000 years in China and previous review of 27 studies, or 1736 patients provided specific evidence of the effectiveness of scalp acupuncture (Liu, Li, Wang, Zhou, & Zhuang, 2019). Scalp acupuncture involves specific acupoints on a patient's scalp located along different lines or zones and results in certain hormone levels improving along with cerebral blood. (Liu, Li, Wang, Zhou, & Zhuang, 2019). The controlled trials that evaluated the effect of scalp acupuncture showed "significant improvements in language comprehension and self-care ability" (Liu, Li, Wang, Zhou, & Zhuang, 2019).

Another promising study was conducted on a set of young autistic males (between 13-27 years old) being given phytochemical sulforaphane, which is derived from broccoli sprout extracts (Singh, et al., 2014). The study participant were given either an oral dose of the phytochemical sulforaphane or a indistinguishable placebo, they were given either of these for 18 weeks and then given nothing for 4 weeks; after 18 weeks the group given the placebo experienced minimal change, but the group given the phytochemical sulforaphane had substantial improvements of behavior, however once the dose was stopped regression soon followed (Singh, et al., 2014).

An unlikely focus in the research on autism is robotics. Three pairs of children with autism, including a set of twins, a second set of siblings and a third set of just classmates were

enrolled in a 12-session robot-assisted group-games program (Taheri, Meghdari, Alemi, & Pouretmad, 2018). The results indicated that all the participants level of severity on the Autism spectrum decreased after the program (Taheri, Meghdari, Alemi, & Pouretmad, 2018). The results of each individual participant were dependent on the level of severity present, but all participants increased in the ability for eye contact and verbal communication (Taheri, Meghdari, Alemi, & Pouretmad, 2018).

Perhaps the most promising future research category in autism is genetics. Autism Spectrum disorder is a highly heritable, as well as diverse set of neurodevelopmental disorders with a incredible heterogeneity, with more than 800 Autism Spectrum Disorder predisposition genes identified to date (Yin & Schaaf, 2017). It has been observed that Autism is more commonly found in males with a 4:1 male-to-female ratio and has a heritability rate calculated at 85-92%, based on twin studies (Yin & Schaaf, 2017). According to Jiani Yin and Christian Schaaf that “even in the absence of an established genetic diagnosis, the chance of ASD recurrence in future pregnancies increases with the number of affected siblings” which means that even if a genetic component has not been found in a diagnosed sibling, the family is more likely to have another child to be diagnosed with ASD. When referencing genetics and Autism research, most used is Mendelian genetics, which refers to the patterns of how genetic traits are passed for parents to offspring (Hindorff, 2023)

ASD can now be identified in 6-37% of cases, with medically complex cases. more likely to have an underlying genetic cause identified. However, a large number of cases remain unsolved, which raises the question about genetic mechanisms beyond Mendelian genetics (Yin & Schaaf, 2017).

The future steps in autism research most likely will involve “identification of shared functional networks across genetic entities, attempts to identify compounds that allow mitigation of the respective functional alterations, and the question of how best to conduct efficacy testing of potential pharmaceutical treatments, using quantifiable outcome measures that are sensitive to short-term changes in behavior, in order to allow for successful translation back to bedside, with the ultimate goal of improving quality of life for the affected individuals and their families” (Yin & Schaaf, 2017).

Training for Healthcare workers such as physicians, nurse practitioners and others is an area that seems to be lacking in regards to the Autistic community. A study was conducted in Connecticut on 1,580 primary care physicians and the level of care their patients with ASD received, of those 1,580 physicians, 346 responded that they provided care to adults with Autism (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). The responses received from this survey revealed that of those physicians that reported, more training in the treatment of ASD and other disabilities was needed (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). The lack of training for physicians and other healthcare workers presents unique challenges to treating patients with ASD in adults and children alike. Adults with ASD needing preventative healthcare is quickly being recognized as a public health issue as these people are living longer and needing the same preventative healthcare as their non-disabled peers (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012).

In 2005, the U.S. Department of Health and Human Services reported that women with disabilities had less mammograms than their non-disabled peers, 65% versus 75% respectively (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). It was also reported that only 37% of adults and children with disabilities received a dental screening compared to the 46% of their non-

disabled peers, it seems there are many reasons for people with disabilities not receiving much needed medical care which included “physician training, comfort levels and reimbursement for care contributing to the lack of quality care available to these people” (Bruder, Kerins, Mazzearella, Sims, & Stein, 2012). Little is known about the healthcare needs of a ageing population with Autism, the specific parameters of need, particularly access to medical care and quality outcomes (Bruder, Kerins, Mazzearella, Sims, & Stein, 2012). Physicians in this study reported the need for additional training and education beyond what they had already received for treating a patient with autism (Bruder, Kerins, Mazzearella, Sims, & Stein, 2012). It is also further noted by the responding physicians that 54.7% of their patients with Autism Spectrum Disorder could not understand and therefore follow medical recommendations, which indicated a need to involve that person’s caregiver for any needed ongoing medical care (Bruder, Kerins, Mazzearella, Sims, & Stein, 2012). The data from this study suggests a need for both providing better and a need for both improving the availability of “community-based geriatric supports and services” as the Autistic community ages (Bruder, Kerins, Mazzearella, Sims, & Stein, 2012).

In terms of medical care for both adults and children on the Autism spectrum, a medical home model is suggested, which would maximize outcomes related to continuing medical services. A medical home model includes ongoing access to healthcare, a usual source of care, person-centered care, a personal doctor or nurse and referrals to specialty care if needed (Bruder, Kerins, Mazzearella, Sims, & Stein, 2012).

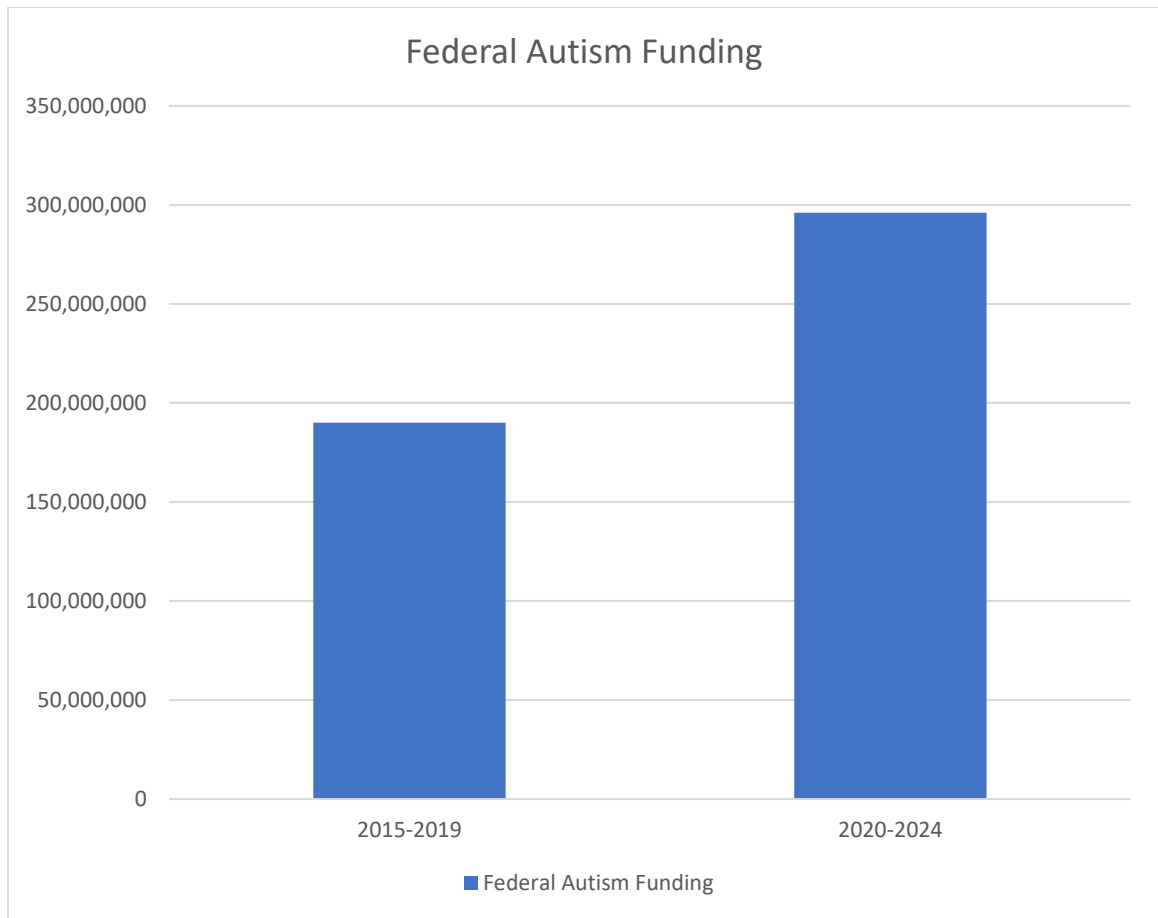
Long-term Resources

A major obstacle for people with autism and other developmental disabilities is access to medical care and only a small number of community healthcare professionals treat patients with

autism and other developmental disabilities (Smith, McCann, Urbano, Dykens, & Hodapp, 2021). People with autism and intellectual disabilities also have a higher rate of comorbidities and often have complex healthcare needs. In general people with intellectual disabilities have poorer health outcomes and a shorter life expectancy (Smith, McCann, Urbano, Dykens, & Hodapp, 2021). Over four thousand records of individuals with autism were reviewed to determine long-term outcomes, only 20 percent of these individuals had a good outcome, around 30 percent had a fair outcome, and over half of those reviewed had a poor outcome (Steinhausen, Mohr Jensen, & Lauritsen, 2016). To relieve some of these healthcare disparities it is crucial that training in the treatment of autism, intellectual disabilities and developmental disabilities in increased in early physician and healthcare professional training and education (Smith, McCann, Urbano, Dykens, & Hodapp, 2021).

It seems that many health-care professionals are ill-equipped to deal with patients with disabilities. A poll was conducted on 714 US physicians and only 40.7% felt very confident in treating patients with disabilities in general, that number only decreased in other studies conducted on patients specifically with autism or other developmental disabilities (Morelli, Crawford, Tanios, Chelko, & Nowakowski, 2023). An additional survey of 427 medical and dental students was conducted to establish their relative comfort in treating patients with autism and intellectual disability and 56% responded that they felt “inadequately prepared” to provide treatment, yet in the same study 58% of the deans of those medical and dental schools responded that the training needed to treat those patients within the group listed above was “not a priority” (Smith, McCann, Urbano, Dykens, & Hodapp, 2021).

The passing of the Autism CARES Act of 2019 set guidelines for federal Autism funding, as you can see in the table below more money has been allocated for the years 2020-2024.



(U.S. Department of Health & Human Services, 2019)

Overall, the long-term outcomes of people with autism have not been studied. There is almost no credible evidence to suggest the long-term effects of an aging population with autism. More research should be conducted to measure the quality of life and life expectancy of people diagnosed with autism.

Conclusion

While the history of autism is rife with heart ache, each new advance in the research and development in the world of autism offers a glimmer of hope to newly diagnosed families. Autistic adults such as Temple Grandin offer a promising future to parents with children who are

being diagnosed at a higher rate than any other time in history. Temple Grandin gave a voice to the autistic community when no other could be found. Maybe children diagnosed as autistic and given the proper support and therapies can go on to live somewhat normal lives, then again maybe not, and either outcome is going to be alright. Autism has come a long way since the 1950's, and while the stigma is still somewhat attached to the label of Autism, due to great advocacy within the autistic community it is becoming a household name. Autism is nothing to fear; parents of newly diagnosed children face so many emotions upon hearing those words "Your child has autism". The range of emotions can go from fear, to mourning the child you feel you will never have and the experiences you may never experience, to relief that you finally have a name and an explanation to the challenges you have been facing.

Rural America covers more than 70 percent of the country (Anarde, 2019). Rural America is years behind urban landscapes due to the lack of services and if services are available, the wait to access those services can take years. There is also a lack of funding for the public-school systems in rural areas making it harder for children to have access to a Free and Appropriate Education. Many children diagnosed with autism will never get the recommended services and therapies due to financial reasons or lack of available resources for outside therapies and rely solely on the public school system. Budget constraints can make getting the proper accommodations for children in the public-school setting seem impossible, sometimes even resulting in lawsuits. For the families that are financially able to take the necessary action against schools to fight for the needed and deserved supports, ironically are also the families that can afford to have the needed therapies elsewhere. Some public-school systems in urban areas offer what is known as extended school year attendance, which is still shortened for summer break, but still more than most rural schools offer. Most schools are in attendance for roughly

170-185 days per year, extended school year is in attendance for around 200 days (Barnard-Brak & Stevens, 2021).

Services and housing for older Americans is scarce in rural areas for people with the complex needs of Autism (Anarde, 2019).

More training for healthcare professionals is desperately needed to ensure there is an appropriate level of support for individuals with autism as well as their families. Many healthcare professionals have never had experience or training in how to deal with the challenges unique to an autism diagnosis.

More and better treatments for the core symptoms of autism are needed. Applied Behavior Analysis is not well received in the autistic community. Young adults with the diagnosis of autism have been very vocal in their outright dislike of the even the idea of ABA therapy but there is not any research backed treatments for autism to take its place. Some vocal proponents of ABA therapy call it outright abuse and claim they have been permanently harmed by the practice in childhood. The ASD community can have a higher rate of suicide ideation than neurotypical peers (Storch, et al., 2013) although the cause for this is unknown.

We need to do better for the youth of America, specifically for the youth that will be aging with a diagnosis of ASD. More long-term residential facilities are needed for the children who will carry the diagnosis of autism into adulthood. Even with the state programs that make it possible for children to stay with their parents into adulthood, these parents are aging as well and will not be around to care for their elderly children, these disabled adults will need placement in facilities designed to deal with those specific challenges after their parents are no longer alive.

As an autism parent, I can assure you that the prospect of my child's future is scary and overwhelming. I do not know what his future hold after I am no longer here, but I can

assure you that while I am here, I will fight every day for his right to be here and be treated with dignity and respect.

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