

A partnership among Keystone College, King's College, Luzerne County Community College, Marywood University, Misericordia University, Penn State Wilkes-Barre, The Commonwealth Medical College, University of Scranton & Wilkes University

AUTISM IN LACKAWANNA & LUZERNE: PUBLIC HEALTH, RESOURCES, AND PUBLIC POLICY CONSIDERATIONS

An examination of the extent of Autism Spectrum Disorders (ASD) in Lackawanna and Luzerne counties, resources, and insurance challenges.

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Introduction

The purpose of this paper is to provide the Lackawanna and Luzerne County communities with an informative outlook of the region's population that is affected with Autism Spectrum Disorders, the resources, and public health and public policy considerations. Issues will be raised and presented as they are understood by The Institute, and recommendations to address the issues will be presented. The Institute will illustrate how increased resources within the region and legislation are needed to serve the growing population of adults and children diagnosed with Autism Spectrum Disorders.

Much of the information that is available to The Institute regarding Autism Spectrum Disorders is retrieved from government sources, research centers and advocacy groups for individuals with Autism Spectrum Disorders; and websites of local service providers. As such, this paper is not intended to be a comprehensive view of individuals with Autism Spectrum Disorders, but an informative piece to address regional issues surrounding those living with Autism Spectrum Disorders.

First, a compilation of information regarding Autism and other Autism Spectrum Disorders, including the symptoms and possible risk factors, will be presented. Following that, Autism spectrum disorder population rates in Pennsylvania as a whole and in our local community of Luzerne and Lackawanna Counties will be established, as well as estimates for future populations. Resources and services for individuals with an Autism spectrum disorder will be identified, and major service providers in our area will be listed, followed by health insurance implications.

Background

Mental illnesses are invasive and can disrupt entire lives, both of those affected and the guardians or caregivers of those affected. These disorders can inhibit a person's performance in social settings, as well as at school, work, or in the home. They can also be physically impairing, or reduce an individual's ability to function independently. Having a mental disorder or mental illness is often stigmatized or discriminated against in society. People living with mental disorders can be misjudged or mistreated because of the way they act, think, or look. That said, there are some mental illnesses that are surrounded by more stigma and misunderstanding than others. Further, the resources to treat mental illnesses are much more limited than those for physical illnesses. Autism Spectrum Disorders are often surrounded by misunderstanding and limited resources.

Autism, or more specifically, Autism Spectrum Disorders are mental disorders which affect multiple aspects of an individual's life, including behavior, communication, daily function, and social skills. The classification of "Autism Spectrum Disorders" encompasses five specific conditions, which are collectively referred to as Autism—often by mistake. The five disorders



which fall on the Autism spectrum are Pervasive Developmental Delay, Autism (often termed "autistic disorder"), Asperger's Syndrome, Childhood Disintegrative Disorder, and Rett Syndrome. These disorders are generally characterized by impaired communication (verbal and nonverbal), deficits in social –emotional reciprocity, and deficits in developing, maintaining, and understanding relationships, as well as repetitive movements and resistance to change. Additional diagnostic criteria dictates that normally the symptoms are present in an early developmental period, however they are not fully apparent until the child is presented with the situation. There is significant impairment in functioning; and finally, there is no other explanation such as a specific intellectual disability or a global developmental delay. There are a wide variety of symptoms associated with Autism Spectrum Disorders, and no individual with this classification of disorder exhibits these symptoms in the same manner as another individual, or to the same levels or extremes. There are a series of risk factors for Autism Spectrum Disorders; correlations have been established between risk factors and Autism disorder prevalence, but research has not yet uncovered any causal factors of the disorders. These risk factors can include various biological, genetic, and environmental elements. 1,2

In the 5th edition of the Diagnostic Statistical Manual, Autism Spectrum Disorders can have varying levels of severity, wherein the symptoms of the disorders are exhibited more or less strongly. The levels of severity also affect the individual's ability to function in social settings, as well as their ability to perform daily tasks. There are three specific levels of severity in which Autism spectrum disorder patients are classified.

Level three is the most dependent severity level, in which individuals are almost wholly dependent on external supportive services. They are often severely lacking the ability to communicate, and their repetitive behavior, including rituals, often will severely interfere with their ability to function. Verbal and nonverbal social communication skills are also impaired that affect functioning. As a result, there is very little initiation of social interactions, and minimal response to social overtures from others. Additionally, individuals in level three can be extremely difficult to refocus onto other interests on which they are not currently fixated.

Level two severity indicates that the patient will require a substantial amount of supportive services, with evident impairment in their communication skills as a whole. This is apparent even while receiving assistance. Their repetitive behaviors and fixations are often obvious to observers, and they will often become frustrated or distressed when interrupted. Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts.

Level one severity is the lowest level of support in which individuals with Autism Spectrum Disorders can be placed. These patients require support, but to a lesser extent. Their



inflexibility of behavior causes significant interference with their functioning in multiple contexts. There is also difficulty found in the switching of activities. Their repetitive behavior causes interference in some situations, and they will resist attempts to be interrupted or distracted from their repetitive behaviors. ^{3,4} Without support being present difficulties in social communication causes notable impairments. Difficulty initiating social interactions and/or showing interest is also evident in level one, which results in attempts to make friends to appear odd and typically unsuccessful.

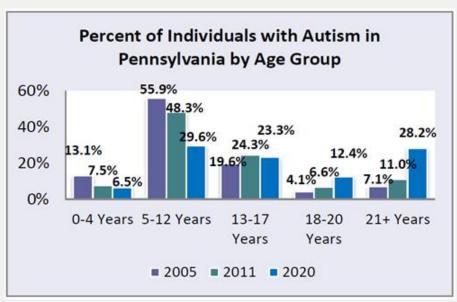
There is no cure for Autism Spectrum Disorders, nor are there any treatments for the symptoms of the disorders. Instead of treatments, the medical and psychological professions have developed intervention programs in an attempt to improve the quality of life and functional development of their patients. There are a variety of interventions, with different approaches to managing the disorders. The most common research-based intervention is a therapeutic approach. In this approach to the disorder, behavioral therapies are applied, using a method known as Applied Behavior Analysis (ABA). Applied behavior analysis (ABA), is defined as the process of systematically applying interventions based upon the principles of behavioral analysis to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement of behavior. ⁵ There are other behavioral therapies that can be used in conjunction with, or in place of Applied Behavioral Analysis. Physical and occupational therapies are also applied in the therapeutic approach, with the goal of improving basic physical skills. Another approach to Autism spectrum disorder interventions is medicinal, in which psychoactive drugs are used to mitigate the tertiary symptoms of tantrums and anger in some patients with Autism Spectrum Disorders. Other interventions include dietary or alternative medicine approaches. These approaches often lack research-based support, and can be employed outside of physician recommendation. It is not uncommon to see complimentary approaches to interventions, where parts of the therapeutic, medicinal, or alternative approaches are utilized to better suit the patient's needs. 6

Not all interventions focus on individuals with Autism Spectrum Disorders. Because these individuals often require external support, they are surrounded by parents, family, or other caregivers. There are interventions and training programs aimed at the support groups and caregivers for individuals with Autism Spectrum Disorders, with the intent of increasing the quality of life, the quality of relationship, and overall happiness of all parties involved while lowering frustration. These programs are typically outside standard treatment plans for individuals with Autism, as they more closely involve the support group, and require educating and training individuals around the patient. Research regarding these parental interventions and training programs indicates that there is a noticeable increase in quality of relationship and



overall life satisfaction between the individual affected with Autism spectrum disorder and the caregiver. ⁷⁸

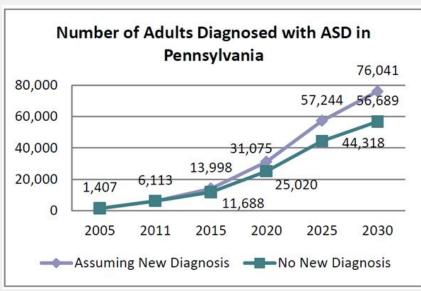
In Pennsylvania, there were roughly 20,000 individuals living with Autism and other Autism Spectrum Disorders in 2005. As of 2011, this number rose to upwards of 55,000 individuals. The exact causes of ASD are not fully understood, so it is difficult to determine why there was such a dramatic increase. However, it is possible that the increase in the number of individuals living with Autism Spectrum Disorders may reflect an increase in diagnoses due to an increase in the sensitivity of diagnostic testing rather than an increase in the incidence of ASD. As many as 9,000 of those diagnosed with Autism Spectrum Disorders are over the age of 21.



Source: Pennsylvania Autism Project Final Report

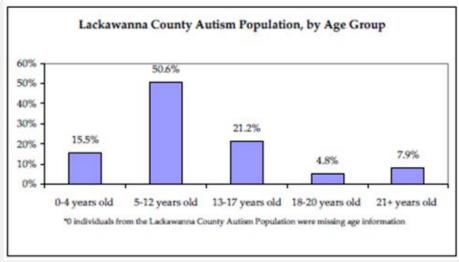
Comparing the Autism Census data from 2005 to the data from 2011 reveals a dramatic increase of over 180 percent in the number of individuals in Pennsylvania with Autism. This also reveals an increase of over 300 percent for adults over 21 who are living with Autism in PA. If this trend were to continue at this accelerated pace, it is expected that there will be upwards of 31,000 adults aged 21+ who are living with Autism by the year 2020, and more than 76,000 by 2030. ⁹





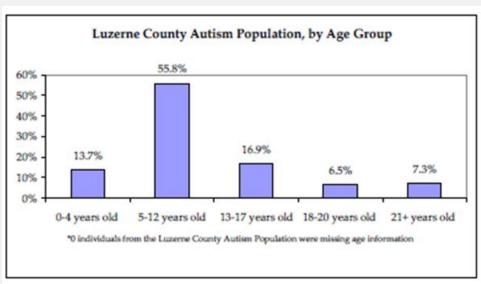
Source: Pennsylvania Autism Project Final Report

Locally, in 2005, Luzerne County had 496 individuals living with Autism Spectrum Disorders, Lackawanna County had 330 individuals living with Autism Spectrum Disorders. Following the state trend for 180 percent increases, in 2011 Luzerne County had increased to 1,151 Autism Spectrum Disorders individuals, and Lackawanna County increased to 905 individuals. For each county, roughly 78 percent of the individuals with Autism Spectrum Disorders were adults over 21 years of age. Particular attention should be paid the 5 – 12 age group, the largest cohort in the region. Since resources for Autism individuals are extremely limited once a person turns 18, therefore, it is imperative to provide children with as much support as possible before they that age out of the systems' services.



Source: Pennsylvania Autism Project Final Report





Source: Pennsylvania Autism Project Final Report

Resources

As indicated in previous sections, there are many individuals in our region who are living with Autism Spectrum Disorders. However, there are many organizations that provide services to these individuals so that they may improve their quality of life and capacity to function independently. This section is not intended to be a complete list of all service providers for individuals with Autism Spectrum Disorders in Lackawanna and Luzerne Counties. Rather, this is intended to represent the best possible listing of resources in our area based on the data currently available to The Institute.

As awareness regarding Autism Spectrum Disorders spreads, and more research is conducted, there is an increasing number of publically available resources and utilities designed to provide information for caretakers or other concerned individuals. Many Autism Spectrum Disorders advocacy groups and government entities publish documents that define Autism Spectrum Disorders, indicate signs and symptoms related to these disorders, and indicate where caretakers may get more information, and assist with locating more localized medical service providers.

The Assertive Community Treatment, or ACT team, formed through each County's Department of Human Services, is a 24 hour a day, seven day a week in-home service team for individuals with mental health or developmental issues. Due to the growth in the Autism and Autism Spectrum Disorders in the local population, there has been an increase in individuals who are enrolled in Assertive Community Treatment services locally, although the current number could not be verified. While there has been long-standing collaborative relationships with the local Autism Coalition and ACT and there is service expertise provided, further analysis of this



apparent trend will be necessary to adequately develop and maintain quality services for those affected by Autism and on the Autism Spectrum now and in the future. 10

These 12 member teams have the capacity to serve up to 75 people, and targets its services to individuals who are at a higher risk of hospitalization. The teams also serves patients recently discharged from Clarks Summit State Hospital who often fail to follow their personal treatment plans. The population serviced by the teams includes adults 18 years of age or older in Lackawanna and Luzerne County areas. Individuals receiving services from the ACT team are not eligible to receive other services, but are permitted to receive ACT services for life. The team serves primarily to reduce hospitalization and institutionalization rates. As reported by the ACT team, their presence has reduced the number of inpatient admissions, which are a costly burden on the Mental Assistance funding program. ¹¹

Children's Service Center of Wyoming Valley offers a multitude of services to the community, including adoption, in-home, outpatient, crisis management, and school based services. This provider offers an Autism Program, which can provide services to both Luzerne and Wyoming Counties, as well as Danville, Hazleton, and Scranton. Among the list of services Children's Service Center provides to the surrounding area, their Behavioral Health Rehabilitation Service is primarily for children with Autism Spectrum Disorders. This service aims to provide services for children with Autism Spectrum Disorders as well as their families. The level of services rendered is determined by a treatment team, which can include a psychologist, behavioral specialist consultant, case manager, therapeutic support staff worker, and other collaborative agencies. The team works to establish a treatment or intervention plan to fit the needs of both the client and their caretakers. These plans can include in-home visits, in-school assistance, or community-related assistance. The CSC reports that it is flexible regarding the days and hours in which it can provide services for individuals with Autism Spectrum Disorders. The treatment plans often include behavioral therapies, such as Functional Behavioral Analysis, Board Certified Behavior Analysis, or Applied Behavior Analysis.

Clarks Summit State Hospital is a psychiatric hospital in the Scranton area that serves 11 surrounding Counties with a combined population of roughly one million. Included in the areas served are Lackawanna and Luzerne Counties. The facility is both Medicare and Medicaid certified to provide services to as many individuals as possible. As of April 2014, Clarks Summit State hospital had 220 patients, half of which were from Luzerne and Wyoming Counties. There is a waiting list for admission to the hospital, but the hospital does work diligently with other programs and service providers to transfer or discharge patients and reduce their waitlist time. ¹³

Commonwealth Health Systems offers a variety of services through its network of facilities. Of their five behavioral healthcare facilities, four of them are within the Luzerne and Lackawanna



County areas. Included in these services are addiction and substance abuse treatment programs, three levels of adult inpatient care, services for both adolescents and children with mental illnesses, as well as a wide variety of therapies. ¹⁴

Friendship House provides a variety of services to children and families throughout Northeastern Pennsylvania, Philadelphia, Pottstown, and Schuylkill County. Specifically, the agency provides outpatient mental health to children, youth and families, and school and Head Start based programs. The Northeast Regional Autism Center located at Friendship House is a state of the art program serving children with autism and their families. The Center's Early Intensive Behavioral Intervention (EIBI) program is a center-based program in Scranton for children ages 2 to 6. The program offers full-day state-of-the-art intensive and comprehensive treatment based on the principles of Applied Behavior Analysis. Applied Behavior Analysis is a research based, data driven model proven most efficacious in the treatment of Autism Spectrum Disorders. The staff to child ratio is one-to-one and the clinical teams are comprised of individuals certified by or in pursuit of certification by the Behavioral Analyst Certification Board (BACB).

The focus of this program is to teach basic learning and language skills and adaptive behaviors across the domains of communication, socialization, and daily living skills. The program immerses children in a social and language rich environment where children are able to generalize acquired skills to the natural environment. The goal is to maximize young children's abilities at a critical stage in their development, when their brains are most responsive to acquiring and generalizing adaptive skills.

Children who are candidates for Early Intensive Behavioral Intervention (EIBI) have been diagnosed with an Autism Spectrum Disorder (ASD) under 18 months of age.

The Northeast Regional Autism Center at Friendship House also provides Home and Community-Based Autism services to children throughout Lackawanna County ranging from early childhood to age 21, using a tiered approach.

For pre-school children, Friendship House offers an intensive behavioral intervention home-based program that focuses on increasing basic learning and language skills.

For school-aged children, interventions may include Therapeutic Staff Support (TSS) in school, Licensed Behavioral Specialists, and/or mobile therapy to help the individual learn appropriate adaptive behaviors and decrease behavioral symptoms that may impede learning. In addition, home programming may also be a component of a child's treatment plan. Home programming for school-aged children typically involves increasing daily living, and socialization while also decreasing maladaptive behaviors. Other individuals on the Autism Spectrum may benefit from



interventions that are based in the community in which they live to encourage and utilize services/resources available to all of members of our society.

Geisinger's Center for Autism & Developmental Medicine Institute (ADMI) in Forty Fort includes clinicians, researchers, educators, and scientists. ADMI offers a comprehensive menu of clinical services for children and families, including neurodevelopmental assessments, psychological and educational testing, genetic and medical diagnostic testing, genetic counseling, medication management, speech/language assessments, and behavioral evaluations. ADMI also conducts research, works with higher education institutions to develop training for students, and conducts educational seminars.

Keystone Human Services offers a wide range of services to individuals with Autism and other Autism Spectrum Disorders across Pennsylvania and Connecticut, but a small selection of the provided services are available in Lackawanna, Luzerne, and Wyoming Counties. The services available include Community Homes, Adult Day Services, an Autism Waiver Program, Independent Living Services, Individual/Family Support Services, Supported and Supportive Living Services, and short term Respite Services. Service dogs are also offered in a variety of settings and specializations for those who need them. Some services offered by the Keystone Human Services, such as the Medicaid Autism Waiver Program, are extremely limited, and can only serve 200 people. Even though this program is aimed at individuals over the age of 21, it provides an extensive amount of services, including Assistive Technology, and Supported Employment services to those with Autism Spectrum Disorders. ¹⁵

Step By Step offers services to Counties across Pennsylvania. In the Northeast region, they provide services in Carbon, Lackawanna, Luzerne, Monroe, Pike, Susquehanna, Wayne, and Wyoming Counties. The services they offer include behavioral health rehabilitation, community residential rehabilitation, mobile psychiatric rehabilitation, as well as supportive independent living services. Some of these services are targeted specifically at children and youth, but the majority of the provided services do not appear to be age restricted. ¹⁶

The NHS School of Scranton has made steps to assist those with Autism Spectrum Disorders. The school has expanded its services to include Emotional Support along with various Autistic Support classrooms. These classrooms focus on building resiliency in their students. With connections and support through the local community the school has even had the opportunity to participate in a skiing program with the Special Olympics along with developing their own basketball team. Other activities and events the NHS School of Scranton take part in include, Learning About Embryology, Bully Prevention, Student Appreciation Month, Cake Bake-Off, and Yoga. ¹⁷



The New Story School located at 751 Keystone Industrial Park, Unit 1 Dunmore teaches students the necessary social, behavioral and educational skills they need to be successful in life – and return to their home school as quickly as possible.

The school provides emotional support and autism support classrooms for students K-21 years of age. The staff is dedicated to ensuring that each student has an opportunity to grow to their fullest potential.

Students who attend the school maintain a regular academic schedule, including reading, math, social studies, and science. The staff teaches students life-long skills on a varying degree of levels in areas such as appropriate behaviors, self-sufficiency, personal hygiene, and vocational skills. New Story students also learn how they can be a productive member of their community.¹⁸

The Arc of Luzerne County is a private, non-profit, membership based organization guided by a volunteer board of directors. The Arc is devoted to providing information, encouraging the development of well-coordinated and integrated services, monitoring the quality of programs, and most importantly, working on behalf of the person with Intellectual and Developmental Disabilities (IDD) and his/her family to assist in the enhancement and development of skills, attainment of services, and resolution of problems. The Arc has conducted many programs in support of individuals with Autism Spectrum Disorders. Such programs include Kids on The Block Puppets, Independent Monitoring for Quality, Community Resource Center, PA Independent Living Radio Show, and TRACE- Transition to Community Employment. ¹⁹

The Graham Academy in Luzerne County provides a special education for children living with autism or behavioral challenges. It focuses on education for children in grades K-12, with an objective of personal development. Students receive support and attention that fosters emotional confidence and social growth amongst their peers. ²⁰

The Scranton Counseling Center provides Autism Programs for children. These are available to children with a diagnosis within the autism spectrum classification. Treatment utilizes the highly effective, scientifically documented methods of applied behavioral analysis. The preschool program offers intensive, discreet trial therapy in the home, while the school age program offers behavioral techniques prescribed by a psychologist and implemented by Scranton Counseling Center's trained staff. All training is in accordance with nationally accepted standards. ²¹

Friendship House, Scranton Counseling Center, Youth Advocate Program, Family Enrichment and NHS of Northeastern Pennsylvania provide Behavioral Health Rehabilitation Services (BHRS) services commonly known as TSS services to school age children/youth with autism.



These services are provided within the school setting and the duration of support for the child is dictated by the child's treatment plan. Typically, a child has a TSS worker assigned during the school day for 3-6 hours.

For school-age children, interventions may include TSS support in school, to help the child learn appropriate adaptive behaviors and decrease behavioral symptoms that may impede learning. In addition, home programming may also be a component of a child's treatment plan. Home programming for school-aged children typically involves increasing daily living and socialization while also decreasing maladaptive behaviors. Other children on the Autism Spectrum may benefit from interventions that are based in the community in which they live to encourage and utilize services/resources available to all of members of our society. These services are paid for through Medical Assistance or HealthChoices.

Typically, adults with autism have access to day programs (intellectual disabilities adult day programs, programs with activities which run for 6 hours a day Monday through Friday) and vocational programs (piece work in a vocational training center like Allied Services or Keystone) with other adults with intellectually disabilities.

Keystone located in Scranton operates 1-2 group homes for 2-4 individuals with autism. Other residential providers like ARC, Goodwill, Saint Joseph's Center, and UCP serve individuals with autism within group home settings with other individuals with intellectual disabilities.²²

Higher education institutions can be another key partner in supporting people with Autism. Misericordia University recently offered a comprehensive workshop on how to facilitate collaboration among professionals working with individuals with Autism. The program, "Autism: Solutions for Successful Collaboration", was designed for professionals and parents of children with autism.²³ Misericordia students have also organized activities and events designed to raise awareness and raise money for Autism Speaks.²⁴

Marywood University has also shown efforts to help aid those with Autism. Their SOAR Program (Students On-Campus Achieving Results) educates a small group of students with Autism at a college level with mentors and job coaches. The program gives the students a sense of belonging and provides them with an opportunity to reach their full potential at a college level. The students gain independent living skills and preparation for gainful employment.²⁵

Insurance Implications

The Mental Health Parity and Addiction Equity Act of 2008 amended the Public Health Service Act, as well as other insurance related acts to help equalize mental health insurance financial requirements with traditional healthcare insurance plans. This helps alleviate some of the financial burden on individuals with Autism Spectrum Disorders, as well as other individuals with mental illnesses. However, the MHPAEA does not require major health insurance plans to



provide mental health and substance abuse benefits; the act only affects those plans which include those mental health benefits to their subscribers already. ²⁶

In addition, in 2008, Pennsylvania passed the Autism Insurance Act. It requires many insurance carriers to cover the cost of assessment and treatment of the Autism spectrum disorder for children under 21 years old and up to \$36,000 per year. Medical Assistance will cover patients enrolled and those whose costs exceed \$36,000 per year. The Act covers diagnostic assessment and treatment to include prescriptions, blood tests, care under a behavioral specialist, applied behavioral analysis and other rehabilitative care, therapy and therapists.²⁷ This law does not apply to individual and small group health plans.

The Affordable Care Act (ACA) does allow children to stay on their parents plan until age 26. Severely disabled adults who remain financially dependent can petition to remain on their parents' plan. The ACA does not offer Applied Behavioral Analysis (ABA), an effective treatment and evidence based treatment for Autism focusing on what precipitates behaviors and how to modify them. While Pennsylvania includes ABA under its 2008 Autism Insurance Act, it does not yet offer it in ACA plans. The Affordable Care Act has removed lifetime and annual caps on health insurance benefits for children, however it still can limit the frequency of therapies. Children with pre-existing conditions cannot be denied and plans cannot drop those enrolled because of a health condition. Now, plans must cover Essential Health Benefits, which include mental health disorders, substance abuse disorders, and behavioral health treatment. Even though these EHBs vary by state, under the ACA, it would be easier to have access to these therapies, regardless of coverage. Still, some beneficial services may still not be covered for all individuals. Federal law states that coverage and benefits must be the same as those provided for physical health by insurers. The government will not override states where the coverage goes beyond these expectations. Under the ACA, this coverage would last until the insured is 26 years of age, and it is higher in some states. It is important to note that children who are denied Medicaid coverage because of the incomes of their families can reapply when they are 18 as a "family of one," thus removing the salaries of their parents from the equation. It is also important to note that families who are denied such claims can appeal to the court systems.

Conclusion

The research and information procured has shown more programs and services for children in our region. Once the patients turn 18 years old, or in some cases 21 years old, they will "age out" of the system and stop receiving most benefits. At present, there are roughly 10,000 adults in Pennsylvania with Autism Spectrum Disorders. By 2020, assuming there are no new patients with Autism Spectrum Disorders, it is expected that there will be at least 25,000 adults in Pennsylvania with an Autism spectrum disorder. There are some services in the area, which are not age-restricted, or are exclusively available to adults with Autism Spectrum Disorders or other mental health issues, but these services may be restricted in other ways, such as their



patient capacity or limited service hours that can be provided. As demonstrated in previous sections, the adult population living with Autism Spectrum Disorders is growing. The services provided to the adult population are not likely to keep up with the shift in population of the age groups. This shift could lead to a major problem in the future, wherein the population of adult individuals with Autism Spectrum Disorders vastly outnumbers the capacity of adult service providers that can effectively treat and provide adequate services for these individuals.

There appears to be a demand for Autism resources that cannot actively be met. It is true that inpatient services are very costly compared to other forms of services, but it is a necessary service that the area desperately needs. For example, Clark Summit State Hospital was able to recently reduce its patient population by as much as 20 percent, due to community reintegration projects, as well as other community mental health services, but there is still a waitlist to be admitted to the hospital and receive services. There is no description of the mental status of the patients or the percentage with Autism, but it serves as an example that community reintegration projects can be successful in the reduction of patients with mental disabilities. In order to serve the aging population living with Autism Spectrum Disorders, service capacities need to be increased, remove or reduce age service restrictions, or create new initiatives that specifically assist the adult population.

Adult Autism services often operate with the goal of improving daily independent functionality, so that the patients can be productive members of society. Assisted living and independent work programs help make that goal a reality. Steadily increasing the service capacity of these programs to accommodate the growing adult population living with Autism Spectrum Disorders can help the area achieve the goal of allowing a greater amount of people to live more independently. However, many adults with Autism cannot function independently, and therefore a higher level of services is required.

An ongoing issue for most individuals seeking healthcare services has always been insurance and the services for which the insurance will provide coverage. This is present for patients in the Autism spectrum disorder population as well. Insurance companies may have specific services allowed for each disorder, but the allowed services may not be as efficacious for each individual. As mentioned in the introduction to this project, each individual manifests their disorder and symptoms differently, and to varying degrees. This can lead to some individuals having limited access to services, or only have covered services that do not provide the levels of care or support the individuals may require. Within the past four years, major changes have taken place in the insurance field. These changes have increased mental health service dollar limits, stabilized financial burdens of individuals receiving mental health services, and have attempted to address the discrepancy between psychical and mental manifestations of disorders. ²⁸



Pennsylvania however still has the age caps on for Autism treatment. States like California, Indiana, Massachusetts, New York, and Wisconsin, and Indiana to name a few, do not have age caps on Autism benefits.

Policy Recommendation

Encourage the Commonwealth of Pennsylvania to lift the age caps on Autism benefits in order to adequately provide treatment, programs, and services to the growing number of Pennsylvania adults living with Autism Spectrum Disorders.



Endnotes

- ²³ Misericordia University. (2015).
- ²⁴ Misericordia University. (2015).
- ²⁵ Marywood University. (2015).



¹ Huquet G, Ey E, Bourgeron T. The genetic landscapes of autism spectrum disorders. Annu Re Genomics Hum Genet. 2013; 14: 191-213

² Autism Science Foundation. What is Autism? (2014).

³ American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.)

⁴ Carpenter, L. (2013). DSM¬5 Autism Spectrum Disorder.

⁵ Baer, D.M., Wolf, M.M., & Risley, T.R. (1968). "Some current dimensions of applied behavior analysis." Journal of Applied Behavior Analysis

⁶ Center for Disease Control. Treatment. (2014, March 13).

⁷ The Growing Trend toward Mandating Autism Coverage. (2009). The Council for Affordable Health Insurance, (152).

⁸ Tellegen, C. L., & Sanders, M. R. (2014). A Randomized Controlled Trial Evaluating a Brief Parenting Program With Children With Autism Spectrum Disorders. *Journal Of Consulting And Clinical Psychology*, doi:10.1037/a0037246

⁹ Shea, L., & Mandell, D. (2009). Pennsylvania Autism Census Project: Final Report. Harrisburg: Bureau of Autism Services.

 $^{^{10}}$ Luzerne County PLanning Document For 2012/13 Human Services Block Grant.

¹¹ Wilson, D. (2014). Luzerne-Wyoming Counties Mental Health and Developmental Services Advisory Board Meeting (5/22/2014). Luzerne County.

¹² Children's Service Center. Behavioral Health Rehabilitation Service (2014).

¹³ Pennsylvania Department of Public Welfare. Clarks Summit State Hospital. (2014).

¹⁴ Behavioral Health Center. Commonwealth Health (2014.)

¹⁵ Keystone Health Services. Autism Services. (2014).

¹⁶ Step by Step: Opening the Doors to Independence and Opportunity. (2014).

¹⁷ NHS Human Services. (2015).

 $^{^{18}}$ Martin, James. Autism Services in Lackawanna County. (2015).

¹⁹ The Arc of Luzerne County. (2012).

²⁰ The Graham Academy. (2013).

²¹ Scranton Counseling Center. (2008).

²² Martin, op.cit.

²⁶ The Mental Health Parity and Addiction Equity Act. Center for Medicare and Medicaid Services (2014.)

²⁸ The Growing Trend toward Mandating Autism Coverage. (2009). The Council for Affordable Health Insurance, (152).