

4-2019

# Autism Spectrum Disorder: Solutions for Improved Care

Virginia Richmond  
Germanna Community College

Follow this and additional works at: [https://commons.vccs.edu/student\\_writing](https://commons.vccs.edu/student_writing)

Part of the [Insurance Commons](#), [Mental Disorders Commons](#), and the [Rehabilitation and Therapy Commons](#)

---

## Recommended Citation

Richmond, Virginia, "Autism Spectrum Disorder: Solutions for Improved Care" (2019). *Student Writing*. 27.  
[https://commons.vccs.edu/student\\_writing/27](https://commons.vccs.edu/student_writing/27)

This Paper is brought to you for free and open access by the Student Scholarship and Creative Works at Digital Commons @ VCCS. It has been accepted for inclusion in Student Writing by an authorized administrator of Digital Commons @ VCCS. For more information, please contact [tcassidy@vccs.edu](mailto:tcassidy@vccs.edu).

Autism Spectrum Disorder:  
Solutions for Improved Care  
Virginia Richmond  
Germanna Community College

### Abstract

Children that are on the Autism Spectrum are suffering every day because they aren't receiving the care and treatments that are necessary to thrive in adulthood. Caregivers to those on the spectrum are not handling the stressors of parenting those on the spectrum correctly.

Implementing self-care techniques for themselves will have a positive impact on the child.

Savant skills and obsessions are a common trait in those with autism, and if these are encouraged and guided, it may lay the foundation for a successful career in the future. It is important that the child have a mentor that can help guide these abilities, as well as help with everyday tasks such as social skills and hygiene. Another problem is insurance company policies in Virginia. They have an age and dollar cap for their services, which prevents younger and older people on the spectrum from receiving treatment. These policies need to be dissolved. Children in rural areas, such as Lake Anna, are finding it difficult to receive prompt therapy services because companies are having a hard time placing a clinician with a child that lives so far away. If they offered Telehealth services, this issue would resolve and the child would receive the therapy that they need. This paper argues that children on the Autism spectrum are not receiving the care that they desperately need, which in turn affects their ability to function as an adult.

*Keywords:* Autism Spectrum Disorder, therapy, Caregiver, Insurance Policies, Self-Care, Autism Therapy, Autism Insurance Reform Act, respite



### Autism Spectrum Disorder

Imagine investing \$26,000 a year for your child's specific educational needs, only to be told that she has a sixty-five percent chance of remaining unemployed into adulthood and won't receive a college education? (Autism Society, 2016). This is what parents of autistic children are facing; high out-of-pocket costs for necessary services and treatments, but a low chance of their child thriving as an adult. One in fifty-nine children are diagnosed with autism and the statistics are rising rapidly – almost 15% a year (Autism Society, 2016). Even though autism is becoming more commonly diagnosed in children today, citizens are forking over three times as much, about \$196 billion yearly, for adult autism services (Autism Society, 2016). Why aren't autistic children becoming successful and functioning adults? They aren't receiving the care that is necessary for them to navigate through life's demands. Children with autism are negatively impacted by their caregiver's inability to deal with stress. Maintaining a strong support network and allowing times of respite will reduce stress levels in the caretaker, which will also have a positive impact on the child with autism. Making professional help more accessible to those on the spectrum, implementing stress management options for caretakers, and encouraging self-care techniques in the autistic individual will drastically improve quality of life and treatment outcomes.

Many special needs families feel isolated in their situations, but reaching out to friends, family or even a counselor for support is necessary for both the child and the parents. In *A Parent's Guide to Autism*, Ron Sandison identifies the necessity of caregivers obtaining a strong support network as a step to helping the child with autism. "You cannot help your child if your own life is falling apart. This network of supporters will give you the strength and

encouragement to move forward...You can share information, get advice, and lean on each other for emotional support” Says Sandison (2016). Beyond a network of friends, family and support groups, it may also be necessary to seek professional help from a counselor to work through the stress associated with being a special needs caregiver. Cognitive behavioral interventions for caregivers reduce levels of depression and improve mood states (Romero-Martinez, 2017, p. 166). A study on the effectiveness of cognitive behavioral interventions revealed that parents who attended two-hour therapy sessions every two weeks for eight weeks total had improvement of attention, short and long term memory for words and stories, naming, cognitive flexibility and planning (Romero-Martinez, 2017, p.169). Reaching out to others for help and being surrounded by those that are willing to share some of the responsibilities associated with autism will provide the caregiver with some reprieve and relief that will enable them to have more patience and understanding with their child.

Another stress-reducing tool needing to be utilized by the caregiver is taking times of respite, to have some time away to recharge and recover from the constant task of concentrating solely on a child with autism. Parents can sometimes feel guilty or embarrassed when asking others to watch their special-needs child for a couple days to rejuvenate and they have pushed aside hobbies, friendships, outings and self-fulfilling activities to focus primarily on their child. In 2014, a study was completed on the impact caregiving for an autistic individual has on parent. Out of 224 caregivers, more than half had troubles completing everyday tasks, had mental and physical health problems and financial issues (Hoefman et al., 2014). Multiple studies throughout the years have been conducted to measure stress levels in parents and caregivers to those on the spectrum, and the results are all dreadful. One study revealed that a hormone related to stress was extremely low, indicative of an extremely high stress level similar to soldiers in

combat. Another study revealed that eighty percent of caregivers feel like they are “being stretched to their limits” (Downs Syndrome with a Slice of Autism, 2015). It is crucial for the parent to remain healthy, psychologically and physically. The ARCH National Respite Network says, “Respite services can provide a much needed break away from your caregiving responsibilities. By taking a break, you will become less stressed, better rested and renewed” (Uhl, 2019). There are many avenues when seeking respite care. Case management through social services may have resources for respite care, the area of residence may have local family support services, or family and friends may be willing to care for the child. Seeking reprieve from the daily routines will improve the stress-levels for the caregiver, establishing patience for utilizing other beneficial techniques, such as focusing on how to improve the autistic child’s chance of success later in life and establishing a career.

With the unemployment rate at 65% among young adults with autism, special interests the child has should be encouraged and developed. Many autistic individuals have savant skills, such as computer coding, building and inventing, mathematical giftedness, and musical talents. Groups need to be formed in the community for autistic people to come together and share their interests with each other. These interest groups could be held at a local community center, a school, library or church. This would provide social opportunities, friendships and boost self-esteem as other individuals that are like them take interest in the child’s unique skills. Autism interest groups could also encourage the child to move forward with their talents, which would set the foundation for a particular field of study or career. Temple Grandin, a successful woman on the spectrum, states that 50,000 people with ASD turn 18 a year and “That’s a little late to be thinking about adulthood. I tell parents that by the time their ASD kids are eleven or twelve, the parents should be thinking about what the kids are going to do when they grow up” (Sandison,

2016, p. 43-44). These interest groups will help them to connect with other people that are like them, where interests are developed as a skill that could lead them to a potentially successful career.

A hallmark trait of autism is obsessions, or fixations that the individual with autism frequently or even constantly engages in. Different than interests and savant skills, obsessions can sometimes be considered socially and culturally awkward, but they could be the foundation for a successful and happy life. An example of an individual that turned her obsessions into success is Temple Grandin. Temple used her fixations to revolutionize the cattle stock industry and combined her savant skill of science, her fixations on animals and building devices, to improve the conditions of cattle stock all around the world. She has invented hundreds of equipment devices for this industry that are used globally, as seen in *Figure A1*. Grandin also provided more jobs and opportunities for women. “Until I came along, secretaries were the only women in this industry... I opened many jobs for females in the cattle industry” (Wood, 2016, p. 24). Grandin gives hope to all people that are on the spectrum- she was born low functioning, and now has published many books, has a Ph. D in Science, and her inventions have helped animals and people across the globe. Every autistic individual can be like Grandin if obsessions are nurtured and guided by teachers, the community and caregivers. Grandin explains the autistic’s abilities humorously and perfectly by stating, “Some guy with high functioning Asperger’s developed the first spear. It wasn’t developed by the social one yakking around the campfire” (Wood, 2016, p. 8) Professional counselors, parents, or mentors can help mold this obsession into a platform leading to specific careers or trades.



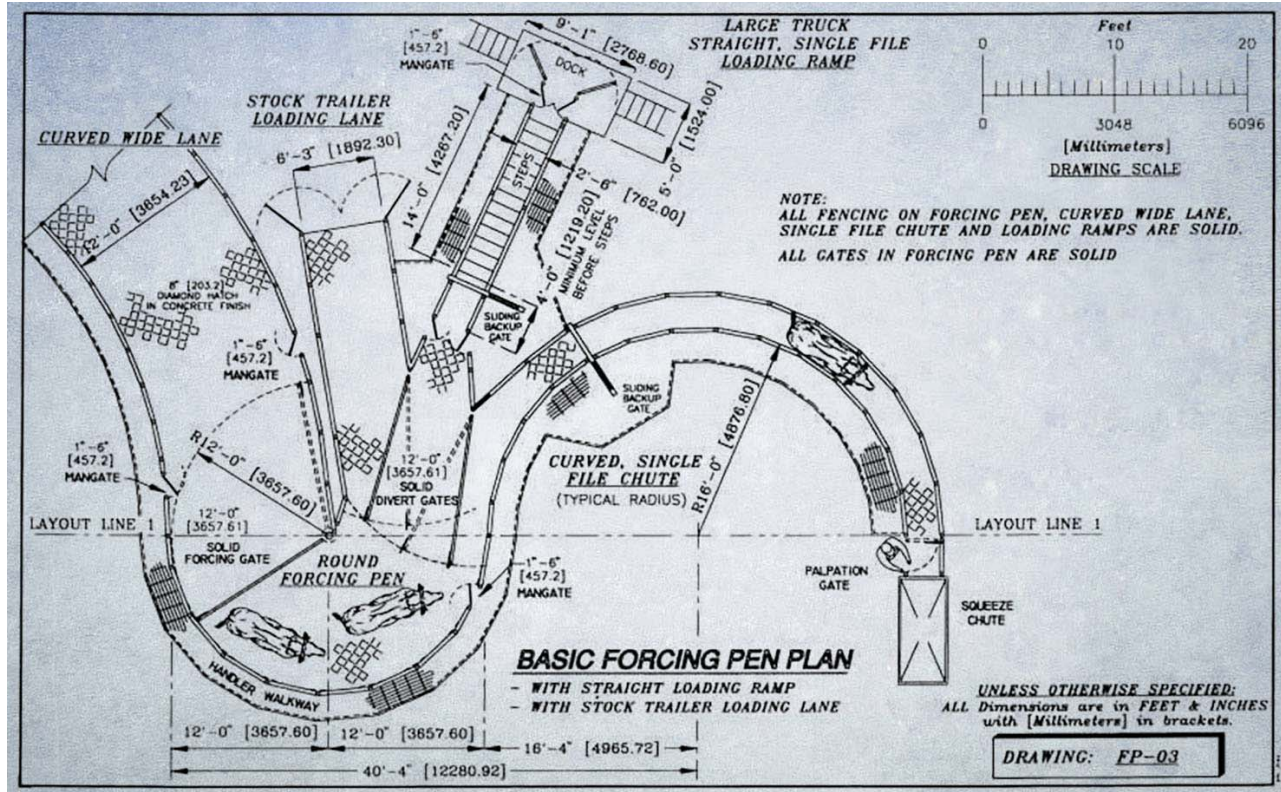


Figure A1. One of Temple Grandin's revolutionary and humane cattle chute invention.

Adapted from Tegün, T. (2016, Dec. 5). Meet Mary Temple Grandin, an Autistic Professor and Engineering Hero. *Interesting Engineering*. Retrieved from <https://interestingengineering.com/meet-temple-grandin-autistic-professor-named-hero-time>

Children with autism face many daily challenges, and having a mentor that can spend quality time with the child would be a benefactor in social, cognitive and emotional development. Mentors can be a close friend, educator, or an individual in the community that can connect with the child. (Sandison, 2016, p. 63-65). A mentor voluntarily and desperately wants to see the child improve and succeed. The mentor and child can participate in activities around the community together, using this as a social development tool. A mentor can also work with the child on hygiene and daily tasks, gently and patiently leading the child. Emotion control is

another area of concern that mentors can help the child with. In *A Parent's Guide to Autism*, Dr. Laura Hendrickson says, "It's important to understand that autism spectrum anger is different from typical anger...your spectrum child can come completely unglued without even realizing it, until he's totally out of control, and it can happen almost instantaneously" (Sandison, 74). A mentor can assist a caregiver and collaborate with them on how to effectively solve angry outbursts. Most of all, a mentor will be a connection that the child will come to love and depend on. Having a friend and leader outside of the clinical and educational setting that can direct, redirect and connect with the child on the spectrum will improve the overall quality of other services being received, and can also be an alternative for treatments that insurance will not cover.

An age limit and annual maximum benefit amount on autism services covered by insurance in Virginia have made it difficult and even impossible for an individual with autism to obtain coverage for necessary treatment. Insurance companies need to dissolve the age limit and maximum coverage amounts so that autistic children and adults may receive the treatment that is necessary for their condition. Some progress has been made over the past five years so that autism services are more obtainable and affordable. By 2015, 43 states had passed an Autism Insurance Reform Mandate (AIRM) which required insurance to cover autism services (Cernias, 2016, p. 1). These mandates, however, differ from state to state, which has parents moving to other states just to receive affordable care for their child. Virginia's AIRM states that insurance policies are required to provide coverage for autistic individuals from age two to six and then it will be the insurance's decision on whether or not to continue services after this age (LIS, 2019). The maximum annual benefit coverage is \$35,000 for applied behavioral analysis therapy, or ABA<sup>1</sup> (LIS, 2019), which is a highly recommended treatment for autism. Many children,

especially higher functioning individuals, do not receive a diagnosis by the age of six, and by then the out of pocket costs for ABA alone is extensive, ranging from \$30,000 to \$100,000 a year depending on the child's needs (Cernias, 2016, p. 9). Virginia should follow California's AIRM model. California is a coveted state to live in for an autism family because their AIRM mandates that insurance provide services regardless of age and also does not have a dollar cap on these services (Cernias, 2016, p. 17). California achieved this type of mandate because along with concerned parents and families, multiple autism awareness and advocacy groups began petitioning and sending letters to state politicians (Cernias, 2016, p. 21). Advocacy groups, parents, teachers, or anyone that is aware of the dire need for changes in Virginia's AIRM needs to begin petitioning for better coverage of services for the autism community, fighting for the elimination of age and dollar caps. A revision of Virginia's AIRM could potentially pave the way for other non-traditional therapy techniques, such as telehealth services, to be more widely available and accessible to those that desperately need them.

Many children are put on long waiting lists because they live in rural areas, and therapy companies can resolve this issue by providing telehealth ABA therapy. Most service providers are located in cities, making it difficult to place clinicians with autistic children in areas such as Lake Anna. Brendan, a child on the spectrum that was experiencing a cognitive regression, lives on Lake Anna and had to wait five months before a clinician was willing to travel the forty-five minutes from Fredericksburg to his home. Brendan is nine years old, and his time is limited, as

---

<sup>1</sup> Applied Behavioral Analysis therapy is one of the few treatments for autism that has been subjected to scientific research, and has been proven to be effective. Teaching through the use of "discrete trials," therapists and family members work as a team to create a highly structured and consistent learning environment in which the child with autism is rewarded for the mastery of each small step (Cernias, 2016, p. 6-7). ABA therapy can range from four hours a week to forty hours a week, depending on the child's specific needs.

his insurance has decided to discontinue coverage after he turns ten. His mother is a single mom that cannot afford the therapy without insurance coverage. There is one resolution to this problem so that children like Brendan can receive the care they need, when they need it; Autism service providers should offer telehealth ABA therapy. Telehealth therapy, which is video conferencing with a doctor for a therapy session, has been proven effective in Iowa. Vanderbilt's Treatment and Research Institute for Autism Spectrum Disorders provides families with an iPad, a tripod and weekly sessions via telehealth (Farmer, 2016). Vanderbilt's Telehealth Therapy was done at less than half the cost as regular ABA therapy, and cut the necessity of traveling to the patient's home (Farmer, 2016). ABA companies in Fredericksburg need to offer Telehealth Therapy for their clients that live in rural areas, so that the waiting period is reduced and the child receives the immediate care that he needs.

Children on the autism spectrum are suffering from lack of care and quality of care, and if the solutions proposed are implemented, the outcome for the child will be positive. The primary stopper to quality care lies with a caregiver that has not equipped themselves to handle the stress that comes with raising a child on the spectrum. Success and progress in the child begins with the caregiver, whom should be connect to those that can support them and give them a well-needed break. The autistic individual should also be engaged in their own support networks, connecting with other autistic individuals that can share their interests and passions. In *A Parent's Guide to Autism* Sandison says, "... encourage your child to learn information on a particular passion, but also help him or her to broaden the topics they study" (2016, p. 37). Along with caregivers and interest groups, a mentor can also encourage the child through their endeavors, as well as help with daily tasks that need to be accomplished. Also, the barrier Virginia insurances have created on access to autism services can be dissolved through petitions

being circulated among communities, advocating for the elimination of policies that make it difficult to obtain necessary treatment. Early intervention is crucial for a more successful outcome and provides a better chance for future employment and sustainability (Cernias, 2016, p. 8). Local therapy companies can also begin offering Telehealth services for autistic individuals that live in rural areas and are on a waiting list for ABA therapy. The startling sixty-five percent of adults with autism that are unemployed or don't continue their education will drop dramatically when these solutions are implemented. The voices of those with autism are silently begging for a drastic change and a better future, and it's time to make that change. In the words of Kristine Barnett, "Whenever I meet an autistic kid who has made progress, I know that someone fought hard for that kid. No matter what the accomplishment ... I know that someone behind that child believed in him and that they fought for him" (as cited in Sandison, 2016 p. 43). Our community needs to take a stand and fight hard for those on the spectrum, and break down the barriers that are causing them to slip through the cracks and go unnoticed until it is already too late.



## References

- § 38.2-3418.17. Coverage for autism spectrum disorder. (2019). *LIS*. Retrieved on February 21, 2019 from <https://law.lis.virginia.gov/vacode/title38.2/chapter34/section38.2-3418.17/>
- Autism Society. (2016). Retrieved from <http://www.autism-society.org/>
- “Blog #122 ~ Parent Stress and Autism.” 2015. *Down Syndrome with a Slice of Autism*. Retrieved from <https://nickspecialneeds.com/tag/journal-of-autism-and-developmental-disorders/>
- Cernias, A. (2016). “No Imbecile at All”: How California Won the Autism Insurance Reform Battle, and Why Its Model Should be Replicated in Other States. *Harvard Law & Policy Review*, (10)2, 565-596. <http://eds.b.ebscohost.com.ezgcc.vccs.edu:2048/ehost/detail/detail?vid=5&sid=215be6e5-b8bd-48e2-9361-b19f9335c774%40pdc-v-sessmgr03&bdata=JnNpdGU9ZWwhvc3QtbGl2ZSZzY29wZT1zaXRl#AN=116996138&db=a9h>
- Farmer, B. (2018, Apr. 6). Could Telemedicine Work for Autism Therapy? Vanderbilt Experiments. *Nashville Public Radio*, Retrieved from <https://www.nashvillepublicradio.org/post/could-telemedicine-work-autism-therapy-vanderbilt-experiments#stream/0>
- Hoefman, R., Payakachat, N., Exel, J., Kuhlthau, K., Kovacs, E., Pyne, J. & Tilford, J. (2014). Caring for a Child with Autism Spectrum Disorder and Parents’ Quality of Life: Application of the CarerQol. *J Autism Dev Disord*, 44(8), 1933-1945. doi: 10.1007/s10803-014-2066-1

- Romero-Martinez, A., Ruiz-Robledillo, N., Sarinana-Gonzalez, P., de Andres-Garcia, S., Vitoria-Estruch, S., & Moya-Albiol, L. (2017). A cognitive-behavioural intervention improves cognition in caregivers of people with autism spectrum disorder: A pilot study. *Psychosocial Intervention/ Intervencion Psicosocial*, 26(3), 165-170.  
doi:10.1016/j.psi.2017.06.002
- Sandison, R. (2016). *A Parent's Guide to Autism*. Lake Mary, FL.: Charisma Media/Charisma House Book Group.
- Tegün, T. (2016, Dec. 5). Meet Mary Temple Grandin, an Autistic Professor and Engineering Hero. *Interesting Engineering*. Retrieved from <https://interestingengineering.com/meet-temple-grandin-autistic-professor-named-hero-time>
- Wood, A. (2016). *Temple Grandin: Voice for the Voiceless*. Retrieved from <http://eds.a.ebscohost.com.ezgcc.vccs.edu:2048/ehost/ebookviewer/ebook?sid=343a8fc7-e844-4344-8ffc-1126e73b1674%40sessionmgr4006&vid=0&format=EK>
- Uhl, M. (2019). 9 Steps to Respite Care for Family Caregivers and Adults with Intellectual and Developmental Disabilities. *ARCH National Respite Network and Resource Center*, Retrieved from [https://archrespite.org/images/Caregiver\\_Fact\\_Sheets/9\\_Steps\\_IDD\\_Caregiver\\_web.pdf](https://archrespite.org/images/Caregiver_Fact_Sheets/9_Steps_IDD_Caregiver_web.pdf).