

Autism: An Analysis of Research, Practice, and Policies

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Abstract

This study serves to explore the history and innovations of autism and the programs available to people with Autism Spectrum Disorder (ASD). The purpose of this paper is to exploit the lack of attention autism has received worldwide and to display the need for better diagnostic, educational, and treatment programs. A description of the disease, current definitions and typologies, and past stigmatization will be discussed. Additionally, this study will highlight various speculations presented by researchers over the past twenty years. As epigenetics are a new innovation in the world of health, environmental epigenetics will be discussed as possible contributing factors to ASD. Case studies and information about the effects autism has on parents, families, and societies are included. The latter portion of this study will analyze systems and programs in Switzerland and the United States. Programs implemented in India, Spain, and Africa will be discussed as well. Governments must address autism as a priority by working to decrease stigmatization, increase education and training for physicians, enhance diagnostic centers, and drastically reshape education programs for children with autism.

Abbreviations

ASD: Autism Spectrum Disorder

USPSTF: US Preventative Services Task Force

AAP: American Academy of Pediatrics

IEP: Independent Education Program

TEACHH: Teaching, Expanding, Appreciating, Collaborating and Cooperating, Holistic

CSHCN: Children with Specific Health Care Needs

SESI: Specialized Education Services Incorporated

NSP: National Standards Project

ADA: Americans with Disabilities Act

IDEA: Individuals with Disabilities Education Act

DTT: Discrete Trial Training

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Research Questions

Given the significant rise in the number of autistic children, it is important to understand why more children are being diagnosed with this disorder. It is clear that autism is a misunderstood disorder that many people know nothing about. Therefore this study will approach autism by asking the questions: What is autism in terms of the epidemiology and the programs

currently available for children with the disorder? What are we doing wrong and what more can countries do to help those in need?

Introduction

Autism, also known as Autism Spectrum Disorder (ASD), is a rising issue in global health. The disorder has proven to be a complete puzzle for researchers, giving meaning to its logo of a puzzle piece. People are suffering all over the world due to ASD and researchers, parents, and doctors have been unable to figure out why. Accusations after accusations have been made trying to determine the cause of autism, but no concrete answers can be found. The consequences of this disorder have shifted attention from genetics to epigenetics since speculations have supported environmental factors as playing a large roll in the cause of the disorder. Every day rates of autism are increasing, people are suffering, and no one in the world has the information to understand why.

Children with ASD are restricted to living a life where they cannot progress, succeed, or develop as much as other children. Parents are living a life of confusion and disappointment in themselves and their children's physicians. Families are being torn apart due to the incredible stress this disorder puts on everyone involved in the affected person's life. Little societal coherence surrounding ASD causes high stigmatization and a lack of mobilization of treatment facilities. Economically, this disorder is crippling families with medical expenses and treatment/education services, and raising governmental expenses for high cost diagnostic centers and clinical programs. From a political standpoint, governments and communities are being pressed to readdress their education systems, diagnostic centers, IEP programs, and health centers.

Now that some investment has been made, and organizations like the UN have declared their support for autism through events like their World Autism Awareness Day, innovations in

this region of study are in the works.¹ More programs are being developed to treat individuals with ASD and some communities have become more understanding. However, we cannot overlook the many regions of the world where this is not happening- places where old diagnostic and treatment practices ensue. Ignorance prohibits the progression of autism treatment.

Research Practice and Policies

Analysis A: Innovations

Symptoms and Diagnosis

The research that *has* been conducted on ASD is easy to access online. The National Institute of Mental health places the symptoms of autism into two categories: restricted/ repetitive behaviors, and social communication/ interactive behaviors.² Those categories are large umbrellas over the many individualized behaviors autistic individuals display. The organization includes additional symptoms: “very sensitive to light, noise, clothing, or temperature” and experiencing “sleep problems, digestion problems, and irritability.”³ Individuals with autism generally experience super high sensitivity. One autistic girl created a video where she expressed what *she* would see while walking down the street. The lighting in the video is drastically harsher than that of the original video, and she explains that her sensitivity to light inhibits her ability to preform every day tasks without irritation, pain, or distraction.⁴

Due to the symptoms listed above, children with autism often have “meltdowns.” In an online video a young woman with autism explains, “a meltdown can be caused by miscommunication, frustration, anxiety, stress, and overstimulation.” She notes that the best way to help her is by giving her space, quiet, and time. The girl in the video also expresses the fact that once she feels a meltdown coming on no one can do anything to stop it- her body is like “an overloaded computer

¹ "Events Organized In Celebration Of World Autism Awareness Day, 2 April 2014". 2016.*Un.Org*. <http://www.un.org/en/events/autismday/2016/events.shtml>.

² "NIMH » Autism Spectrum Disorder". 2015. Nih.Nih.Gov. <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>.

³ *Ibd.*

⁴ Petronzio, Matt. 2014. "5 Autism Simulations To Help You Experience Sensory Overload".*Mashable*. <http://mashable.com/2014/04/23/autism-simulations/#5v8LENbLDuq7>.

system crashing.” She even goes as far as to explain that she knows this behavior is unacceptable and acknowledges everything she is doing but simply cannot help it, “like a baby.”⁵ In many cases symptoms are very similar to childish behavior and take time to distinguish from simple poor behavior. A “meltdown” can be exhibited as, but is not limited to, temper tantrums, screaming, hitting/kicking, spitting, and stripping. Anyone who has spent time with children, in general, knows that this type of behavior is not uncommon due to the lack of communication and social skills every child faces during developmental stages of life. Additionally, children with autism have a difficult time concentrating due to their heightened senses. In classroom settings of more than five students meltdowns can become difficult for one teacher to handle and therefore be reported as bad behavior.

As there is no real “cause” of ASD many organizations have formulated diagnostic plans and individual development programs for parents, physicians, and the autistic child to ensure that he/she is accurately diagnosed. After diagnosis, access to information on individual treatment plans can be found through reports like the EBP (Evidence-Based Practice) Report, Birth to 5 Watch Me Thrive Report, and the NSP (National Standards Project).

Treatment

Because autism is a biological and spectrum disorder, the treatment must be largely rehabilitative rather than curative.⁶ Some forms of treatment have been developed for ASD. Treatment in this sense does not result in a child being cured of ASD, yet it is simply a form of caring for children to help them develop. Dr. Carminati mentions that treatment programs are necessary to mental health which is necessary to social integration” and she is right.⁷ For individuals with autism living life without treatment is almost not an option. Therapies have been

⁵ "What Is Autism? What Is Autism Spectrum Disorder?". 2016. *Youtube*.
<https://www.youtube.com/watch?v=Flcy0XK5j3I&nohtml5=False>.

⁶ Baker, Jeffrey P. 2008. "Mercury, Vaccines, And Autism". *Am J Public Health* 98 (2): 244-253.
 doi:10.2105/ajph.2007.113159.

⁷ Dysard, Savannah. LetterGiuliana Galli Carminati to . 2016. "Independent Study Project". Email.

created by a number of organizations that stem from research on the brain and on individuals with autism.

Dance movement therapy is a form of creative arts therapy and is used as a method of assessment and intervention for children with autism: “dance/movement therapy occurs within a therapeutic relationship with a credentialed therapist and uses the expressive elements of dance and movement as a method of assessment and intervention.”⁸ This type of therapy has gained attention for its uniqueness and ability “to channel communication into dances of relationship.”⁹ This form of treatment has provided a positive alternative to medication for many children.

The Center for Autism and Related Disorders (CARD) suggests ABA treatment. The organization defines ABA as “Applied Behavior Analysis (ABA) is the application of the principles of learning and motivation from Behavior Analysis and the procedures and technology derived from those principles, to the solution of problems of social significance.”¹⁰ ABA treatment is suggested for children with autism and is recommended in many preschool level schools in the United States.¹¹ This approach works to improve behavior such as “reading, academics, social skills, communication, and adaptive living skills.”¹² The system also strives to make the measurements of the disorder as accurate as possible so there is little discrepancy in the description of the individual’s case. One example of ABA: “if one wishes to teach a child to request a desired interaction, as in “I want to play,” one might first teach subcomponents of this skill, such as the individual sounds comprising each word of the request, or labeling enjoyable leisure activities as “play.”¹³ This form of treatment will not cure the disorder but will strive to

⁸ “Dance/Movement Therapy And Autism”. 2016. *Psychology Today*.
<https://www.psychologytoday.com/blog/meaning-in-motion/201404/dancemovement-therapy-and-autism>.

⁹ American dance Therapy Association,. 2014. *Dance/Movement Therapy & Autism: Dances Of Relationship*. Video. https://www.youtube.com/watch?time_continue=3&v=65DLHYrHlIM.

¹⁰ “ABA Resources: What Is ABA?”. 2016. *Center For Autism And Related Disorders*.
<http://www.centerforautism.com/aba-therapy.aspx>.

¹¹ “Growing Minds And Applied Behavior Analysis (ABA) | Growing Minds Autism Programs”. 2016. *Autism-Programs.Com*. <http://www.autism-programs.com/about-growing-minds/growing-minds-and-applied-behavior-analysis-aba.htm>.

¹² (“ABA Resources: What Is ABA?” 2016)

¹³ *Ibd*

make the most of a child's abilities instead of his/her disabilities. It is important that teachers in mainstream education are trained in ABA so they can understand their autistic students.

Case Study: a school's misunderstanding

The mother of an autistic child explained that her daughter often asked to get up and walk around the school building during class. She always held a string in her hand to keep her calm. When teachers told her no or took away her string she tried to explain but they did not understand and mistook the behavior as acting out against the teacher. The woman was disappointed because her daughter's school did not train their teachers in developmental disorders.

Personal experience with an expert on autism, online 2016

Perspectives from Genetics to Epigenetics

There have been many attempts to link ASD to specific genetic causes but so far no success. Epigenetics focuses on the "system biology" of an organism and is defined by Alycia Halladay at Autism Speaks as "the study of the factors that control gene expression, and this control is mediated by chemicals that surround a gene's DNA."¹⁴ The ultimate goal of combining epigenetics into autism studies is to find conclusive connections that will help researchers better understand the disorder. Autism can be best studied through environmental epigenetics where the environment is defined as any surrounding or contributing factors that may trigger the disorder. This includes factors like parental age when giving birth or the region the mother of the child lived while pregnant. One speculation links heavy metals in the environment to autism. According to research conducted at the University of Texas Health and Science Center "for every 10 miles from industrial or power plant sources, there is a decrease in autism rates."¹⁵ While

¹⁴ Halladay, Alycia. 2016. "What Is Epigenetics, And What Does It Have To Do With Autism?". *Autism Speaks*. <https://www.autismspeaks.org/node/123021>.

¹⁵ Palmer RF, et al. 2016. "Proximity To Point Sources Of Environmental Mercury Release As A Predictor Of Autism Prevalence. - Pubmed - NCBI". *Ncbi.Nlm.Nih.Gov*. <http://www.ncbi.nlm.nih.gov/pubmed/18353703>.

epigenetics is a new field of study, it is predicted to advance the sciences surrounding autism in years to come.

Perspectives from Environmental Factors

Parents

If the professional assessment of your child's "unusual behavior" came back as "inconclusive," all other available resources were exhausted, and there was no one to turn to, how would you feel? The toll this disorders takes on parents comes in the form of emotional and physical time and care. One parent noted that for the past seventeen years she has spent hours every day researching autism, gastrointestinal disorders, medications, and diseases because she cannot find a doctor who can tell her what is wrong with her son.¹⁶ Emotionally, parents are just as clueless as many doctors and when they have nowhere left to turn they blame themselves. They blame themselves for a number of reasons ranging from birthing a child with qualities unsuitable for living, not being able to provide the necessary help for their child in the comfort of their own homes, not having the time or attention span to give their child the attention he/she needs, not having the money to supply suggested drugs or treatment for their child, or simply not being able to spend more than a few hours with their own child before getting frustrated with them. Parents love their children for better or for worse but when they witness their child hitting themselves, not functioning, having seizures, and being bullied, many cannot handle it. It is common for parents of children with ASD to slip into a depression. Often times parents will get a divorce due to the stress and fighting this disorder has created for their relationship. Facing the truth is not an easy step to make and may take years for some parents to do. In one case a little girl with autism noted that after being diagnosed it took about six weeks for her mother and her to

¹⁶ *Personal experience with an expert on autism, in Geneva 2016*

come to terms with the fact that she was “different.”¹⁷ Child-Autism-Parent-Café.com offers assistance in finding schools for autistic children around the United States.¹⁸

Parents are the number one support system for children with autism. ASD is generally diagnosed at the age of two but symptoms are usually noticeable well before then. There have been studies to show “one third to half of parents of children with an ASD noticed a problem before their child’s first birthday, and nearly 80%–90% saw problems by 24 months of age.”¹⁹ In fact, doctors have noticed that parents play a large role in the diagnosis of their child because they see their child every day and can vouch for their unusual behavior. Because “ASD frequently coexists with other cognitive/behavioral/neurological disorders, including intellectual disability, language disorder, attention-deficit/ hyperactivity disorder (ADHD) and epilepsy,” it is difficult to isolate ASD diagnostic symptoms from “normal” childish behaviors or other disorders.²⁰ Even now, a set of observations is needed to appropriately diagnose a child with ASD. Without parental support some ASD individuals are helpless.

Case Study: constant care is needed

As noted by an anonymous source, this woman’s friend had a child who was diagnosed with autism at a young age. His symptoms ranged from being an incredible musician to a brilliant mathematician. However, he had little to no social skills. He needed constant assistance in school settings, at home, and even at the grocery store. When he was about forty-five years old his parents passed away and his life took a drastic turn, because at forty-five he still needed social assistance. His parents had always provided that for him.

Personal experience with an expert on psychology, in Geneva 2016

¹⁷ "A Child With Autism Can Get Their Needs Met... From Preschool To Adult Services.". 2016. *Child-Autism-Parent-Cafe.Com*. <http://www.child-autism-parent-cafe.com/>.

¹⁸ *Ibd*

¹⁹ "Facts About Asds". 2016. *CDC - Facts About Autism Spectrum Disorders - NCBDDD*. <http://www.cdc.gov/ncbddd/autism/data.html>.

²⁰ Gillberg, Christopher, Elisabeth Fernell, and Helen Minnis. 2013. "Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations". *The Scientific World Journal* 2013: 1-2. doi:10.1155/2013/710570.

Speculation 1: Nutrition

Recently nutrition has been a hot topic when discussing possible causes of autism. However, most inquiries result in responses like this one: “My request for an opinion on the topic was passed from one research scientist to the next and across the board, I got the same message: ‘there is no evidence-based data we are aware of.’”²¹ Many individuals with autism have food aversions and sensitivities. Many ASD children also have behavioral issues that make mealtime particularly challenging.²² These issues are so severe that researchers at Marcus Autism Center at Emory University School of Medicine have commenced studies on the eating habits for children with autism. They found “children with ASD are five times more likely to have mealtime challenges such as tantrums, extreme food selectivity and ritualistic eating behaviors.”²³ Those poor mealtime behaviors have, reportedly, been subsided by the removal of two ingredients from some autistic children’s diets. There have been multiple accounts of parents removing casein (milk fat) and gluten from their children’s diets and seeing improved symptoms of ASD. If there is a link between gluten or casein and autism researchers do not have enough evidence to support that correlation and for now, the removal of those foods just fronts the problem of under nutrition in an already picky eater.

Case Study: how diet can help for some

One mother explained that after reading about the effects of gluten, she decided to remove it from her autistic son’s diet. She noted that in one week “it was like a switch was flicked on- he became 80% more responsive.” Since then they have kept gluten out of his diet and seen major results. However, a friend of hers tried this same method and saw no results at all.

Personal experience with an expert on autism, in Geneva 2016

²¹ Katirae, Layla. 2015. "Will My Child Be Born Autistic If I Eat Gmos? A Scientist’S View". *Genetic Literacy Project*. <https://www.geneticliteracyproject.org/2015/01/05/will-my-child-be-born-autistic-if-i-eat-gmos-a-scientists-view/>.

²² Sharp, William G., Rashelle C. Berry, Courtney McCracken, Nadrat N. Nuhu, Elizabeth Marvel, Celine A. Saulnier, Ami Klin, Warren Jones, and David L. Jaquess. 2013. "Feeding Problems And Nutrient Intake In Children With Autism Spectrum Disorders: A Meta-Analysis And Comprehensive Review Of The Literature". *J Autism Dev Disord* 43 (9): 2159-2173. doi:10.1007/s10803-013-1771-5.

²³ (Sharp et al. 2013)

Speculation 2: Vaccination

Vaccination has consistently been linked to autism. The link is between childhood vaccinations containing thiomersal, an organomercury agent, and various diseases/disorders, including autism. However, the CDC released that “between 1999 and 2001, thiomersal was removed or reduced to trace amounts in all childhood vaccines except for some flu vaccines.”²⁴ The CDC even states that due to high speculation of the population, there have been nine studies conducted since 2003 which all resulted in no link between certain vaccinations and autism.²⁵ There was so much speculation that the CDC spent money on thoroughly investigating these allegations. An article from the American Public Health Association dedicated research to the connection between thiomersal and the “American debate surrounding vaccines, mercury, and autism.”²⁶ Because mercury poisoning was linked to severe retardation and other mental and behavioral issues in past accusations linked to a variety of situations, there was a commotion over the little bit of thiomersal found in child vaccinations. It is clear that physicians and parents caring for children with autism generated speculations against thiomersal but not scientists.²⁷ Many articles have since been published which strongly support the connection between vaccine and autism due to its mercury content, but have not been able to prove direct correlation.

Analysis B: Comparative Study

Switzerland

Although Switzerland has begun taking steps towards better education and diagnostic systems for children with ASD they have fallen way behind. A Eurhythmics teacher, Tamaé Gennai Deveaud, noted that in the Canton of Genève programs facilitating the integration of

²⁴ Madsen, Kreesten Meldgaard, Anders Hviid, Mogens Vestergaard, Diana Schendel, Jan Wohlfahrt, Poul Thorsen, Jørn Olsen, and Mads Melbye. 2002. "A Population-Based Study Of Measles, Mumps, And Rubella Vaccination And Autism". *New England Journal Of Medicine* 347 (19): 1477-1482. doi:10.1056/nejmoa021134.

²⁵ *Ibd*

²⁶ (Baker 2008)

²⁷ (Baker 2008)

autistic children in public school classrooms started only ten years ago.²⁸ During this integration students are paired with a government-funded assistant who sits with them in class. However, Tamaé explains that even with this new innovation it is difficult for teachers because they have not been properly trained in managing and guiding autistic children, so it soon becomes frustrating.²⁹ The task of training teachers who wish to be trained has been left to independent and non-government funded organizations.

In Switzerland a not for profit organization was created in December 2007. The organization called Autisme Genève is located in Geneva and serves as the local chapter of the Autisme Suisse Romande. Autisme Genève has six main objectives that truly highlight the difficulties that families face when caring for their autistic child: “fighting for rights of persons with ASD and their families, supplying parents with information about ASD, informing parents about existing services, organizing on a regular basis training sessions for parents, professionals and students, achieving official recognition of the specificities of ASD and promoting suitable educational measures, and obtaining the necessary accommodations and adaptations in schools and at work to include persons with ASD and to enable them to effectively participate in their community.”³⁰ This organizations gives support to families in Geneva so they do not have to face the disorder alone. After speaking to Yvette Barman and Marie-Jeanne, secretary and president of Autisme Genève, it is apparent that the government in Switzerland has provided little support for the autistic community. Yvette noted:

They work “in collaboration with public services, not so much with the schools because in Geneva there is practically no mainstreaming at all for children with special needs and especially not for autistic children. As soon as a child is a bit different they

²⁸ Gennai Deveaud, Tamaé. 2016. Independent Research Study of the Education Systems for Autism in Switzerland. Interview by Savannah Dysard. In Person. Nyon Roulotte.

²⁹ Ibid

³⁰ "Autisme Genève". 2015. *Autisme-Ge.Ch*. <http://autisme-ge.ch/>.

usually get sent away. The tendency is starting to change now because the department of education now has a policy that tends towards inclusion but it is really the beginning.”³¹

The services provided by this organization are free, and while the services provided by the state are also free, the state programs are insufficient because the time each family can have with certain special services is very limited. All schools for specialization are free in Geneva but lack properly educated and trained staff. One effort made by the state was to try and train specialists so they could work properly with autistic children. However, for training to be successful schools must present it properly. Autisme Genève’s report notes, “The type of education provided in specialized institutions includes neither an official curriculum nor any formal assessment of acquired skills.”³² They work off of psychodynamics and “it is not very educative- if the parents are getting a divorce that is why the child cannot learn, something like that.”³³ For example, Yvette explains “we know a family who moved to Geneva for the Early Start Denver model for their child and then when their child was four they moved back to their Canton of Neuchâtel because there he could go to school with someone to accompany him in school.”³⁴ Not every family has the luxury of moving from place to place to access the best education for their child at every age of his/her life. For families who cannot move to Geneva for early education they must take it upon themselves to stay home and work with their child.

The Alternative Report created by Yvette and Marie-Jeanne states “in Geneva discrimination begins as soon as the child is identified as being different; the advocated course of action is then to withdraw the child from mainstream education, thereby taking him/her away

³¹ Barman, Yvette and Marie-Jeanne Accietto. 2016. Independent Research Study of the Education Systems for Autism in Switzerland Interview by Savannah Dysard. In person. Autisme Genève Office.

³² (ALTERNATIVE REPORT SUBMITTED BY 'AUTISME GENÈVE' TO THE COMMITTEE ON THE RIGHTS OF THE CHILD IN CONNECTION WITH THE REVIEW OF SWITZERLAND'S SECOND PERIODIC REPORT TO THE COMMITTEE ON THE RIGHTS OF THE CHILD, 2016.)

³³ (ALTERNATIVE REPORT SUBMITTED BY 'AUTISME GENÈVE' TO THE COMMITTEE ON THE RIGHTS OF THE CHILD IN CONNECTION WITH THE REVIEW OF SWITZERLAND'S SECOND PERIODIC REPORT TO THE COMMITTEE ON THE RIGHTS OF THE CHILD, 2016.)

³⁴ Barman, Yvette and Marie-Jeanne Accietto. 2016. Independent Research Study of the Education Systems for Autism in Switzerland Interview by Savannah Dysard . In person. Autisme Genève Office.

from peers and from a normal social environment.”³⁵ Exiling someone from a group of people, any group of people, prohibits said person to be able to interact appropriately when finally integrated into that group. The DSM-5 guidelines explicitly state “difficulties making friends, difficulties in sharing imaginative play, and absence of interest in others” as criteria for diagnosis of ASD.³⁶ In the case of autism, separating an autistic child from children without ASD means they will lack the skills they already have trouble obtaining and in return encounter more difficulties as they are forced to be reintegrated into society during adulthood. In Switzerland this is an especially prominent problem “since many specialized institutions caring for these children are located away from the city centre and are removed from the social and cultural life.”³⁷ Seclusion is not the answer.

In Switzerland there are no governmental statistics on the number of children with autism. Yvette and Marie-Jeanne noted that the Swiss medical system has not been normalized to match DSM-5, resulting in a lack of strict diagnostic criteria. With the creation of DSM-5 a detailed set of diagnostic is available to begin dissolving this issue of misdiagnosis. Without fully recognizing these new diagnostics some children will be improperly diagnosed and data will not be accurately collected. Without accurate data collection sufficient treatment for autism cannot be correctly delivered throughout the country.

Switzerland has made progress with some aspects of autism awareness such as supporting the EU Human Brain Project at biotech campuses and the EPFL, École Polytechnique Fédérale

³⁵ (ALTERNATIVE REPORT SUBMITTED BY 'AUTISME GENÈVE' TO THE COMMITTEE ON THE RIGHTS OF THE CHILD IN CONNECTION WITH THE REVIEW OF SWITZERLAND'S SECOND PERIODIC REPORT TO THE COMMITTEE ON THE RIGHTS OF THE CHILD 2016)

³⁶ Carpenter, Laura. 2013. *DSM5 AUTISM SPECTRUM DISORDER*. Ebook. 1st ed. American Psychiatric Association. [https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5\(ASD.Guidelines\)Feb2013.pdf](https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5(ASD.Guidelines)Feb2013.pdf).

³⁷ (ALTERNATIVE REPORT SUBMITTED BY 'AUTISME GENÈVE' TO THE COMMITTEE ON THE RIGHTS OF THE CHILD IN CONNECTION WITH THE REVIEW OF SWITZERLAND'S SECOND PERIODIC REPORT TO THE COMMITTEE ON THE RIGHTS OF THE CHILD 2016)

De Lausanne.³⁸ But, the country has a long way to go to ensure families have the support they need. Every organization that was consulted for this project provided a disclaimer at the beginning of their discussion. That disclaimer was that the systems in Switzerland are not good and it would be beneficial to look elsewhere for this review.

United States

In the United States the most recent autism prevalence statistics state 1 in 68 children are currently diagnosed with autism- an increase from the 1 in 88 statistics in 2012. That is, “one out of every 68 eight-year olds in the U.S. has autism.”³⁹ The total costs per year for a child with ASD in the United States was estimated to be between \$11.5 billion - \$60.9 billion (2011 US dollars).⁴⁰ This significant economic burden represents a variety of direct and in-direct costs, from medical care to special education to lost parental productivity. The United States has recognized these statistics and given support to autistic research centers. Still, little is known about the disorder making it difficult for organizations to formulate helpful plans of action for families in need.

In the U.S “one-half of school-aged CSHCN with ASD were aged 5 years and over when they were first identified as having ASD”⁴¹ leaving many children without proper early childhood education. Without the proper diagnosis, lack of research, and lack of information on this disorder, it has been difficult for sufficient education programs to be developed. A chart⁴² also reveals that “fewer than one-fifth of school-aged CSHCN with ASD were identified as having ASD within the first 2 years of life” and “two-fifths of school-aged CSHCN with ASD were aged

³⁸ "The Human Brain Project - Human Brain Project". 2016.Humanbrainproject.Eu.
<https://www.humanbrainproject.eu/>.

³⁹ (Fernell et al. 2015)

⁴⁰ ("Facts About Asds" 2016)

⁴¹ Pringle, Beverly A., Lisa J. Colpe, Stephen J. Blumberg, Rosa M. Avila, and Michael D. Kogan. 2012.*Diagnostic History And Treatment Of School-Aged Children With Autism Spectrum Disorder And Special Health Care Needs*. Ebook. 1st ed. CDC. <http://www.cdc.gov/nchs/data/databriefs/db97.pdf>.

⁴² See Image 2

6 years and over when first identified as having ASD.”⁴³ Unfortunately the USPSTF, the US Preventative Services Task Force, has not endorsed autism screening as a means of prevention. The organization declares that there is not enough information on the subject matter: “The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for autism spectrum disorder (ASD) in young children for whom no concerns of ASD have been raised by their parents or a clinician.”⁴⁴ However, ample research and conclusions have been made by The American Academy of Pediatrics on the benefits of screening and The Center for Disease Control (CDC) suggests a mandatory screening at 9 months, 18 months, and 24-30 months with additional screening as necessary.⁴⁵ The organization also suggests specialists in the field of development pediatrics, child neurology, and child psychology. An increase of specialists will produce a more holistic approach to ASD and allow a pool of information to form. The CDC suggests Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Pivotal Response Training (PRT), and Verbal Behavior Intervention. Those suggestions are made on the basis of research results, conducted in the U.S. The website also provides links to occupational therapy, sensory integration therapy, and speech therapy.⁴⁶ All of those resources give parents and physicians an easy way to quickly access information about this disorder online.

The American Academy of Pediatrics (AAP) has declared their support for the prevention of autism. On their website there are links to children with disabilities and a whole section dedicated to autism. The organization lists information under four categories: “Recent Information, Resources for Professionals and Family, Training and Webinars, External Resources

⁴³ (Pringle et al. 2012)

⁴⁴ "Final Update Summary: Autism Spectrum Disorder In Young Children: Screening - US Preventive Services Task Force". 2016. *Uspreventiveservicestaskforce.Org*.
<http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/autism-spectrum-disorder-in-young-children-screening>.

⁴⁵ ("Facts About Asds" 2016)

⁴⁶ ("Facts About Asds" 2016)

and Information.”⁴⁷ They also highlight the benefits of screening children at a young age. Screening for children with and without prevalent symptoms of autism is an important means of collecting information and contributing to research statistics for this disorder. AAP states “This type of screening can identify children with significant developmental and behavioral challenges early, when they may benefit most from intervention, as well as those with other developmental difficulties.”⁴⁸ The organization agrees, “Early intervention can considerably improve children's long-term development and social behaviors.”⁴⁹ But, after detection, children face many more obstacles.

Of course, there are other roadblocks in the form of autism care in the United States like incurred costs. Children with ASD need constant care and individualized attention. The care cannot come in one form but comes in many forms and usually multiple forms. A CDC article notes “just over one-half of school-aged CSHCN with ASD use three or more health care services to meet their developmental needs.”⁵⁰ This is where government support plays a large part because without policy support families with one or more children diagnosed with ASD will not be able to survive financially. In fact, medication costs alone may have negative affects on families. Medical costs are rising and “almost one-third of school-aged CSHCN with ASD use stimulant medications, one-quarter use anti-anxiety or mood-stabilizing medications, and one-fifth use antidepressants.”⁵¹ For some families the medical costs are simply incomprehensible, not forgetting additional care costs.

Nevertheless, the United States is doing what it can to support and provide adequate care for those living with autism and to cut down unavoidable expenses. The government has instated a program called IEP (Independent Education Program). To get an IEP your child must first be evaluated for disorder. After evaluation, appropriate levels of care are determined and “if you

⁴⁷ "Autism". 2016. Aap.Org. <https://www.aap.org/en-us/about-the-aap/Committees- Councils- Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx>.

⁴⁸ ("Autism" 2016)

⁴⁹ Ibd

⁵⁰ (Pringle et al. 2012)

⁵¹ (Pringle et al. 2012)

think your child's evaluation isn't accurate, you can ask for an independent evaluation [which] will be done by a professional from outside the school district [and] your child's district will pay for that evaluation.”⁵² In the United States children with autism are allowed an IEP free of charge that will evaluate the services a child will need: “Each IEP is designed for one child. Its purpose is to meet that child's specific special education needs. It sets goals and objectives and describes what services a child will receive as part of his or her special education program.”⁵³ It is important to note that the child, the child’s parents, and specialists create an IEP together.

In the United States a number of schools have opened themselves to program assistance for children with ASD. Usually, principals and/or department leaders oversee each autistic child’s individual care. Programs like SESI, Specialized Education Services Inc., provide students with personalized care that will eventually lead to mainstreaming autistic children back into classes with other students. This particular program has spread its efforts throughout 200 school districts: “SESI was founded to provide specialized education programming for students who are not finding success in the traditional classroom due to a variety of intensive special needs that require personalized academic and behavioral interventions.”⁵⁴ Another noteworthy program was created in North Carolina at the University of North Carolina School of Medicine, TEACHH. TEACHH’s mission is to “create, cultivate and disseminate the development of exemplary community-based services, training programs, and research to enhance the quality of life for individuals with Autism Spectrum Disorder across the lifespan,” and the program works to improve individualized care, analyze the physical environment, and surpass standard curriculums.⁵⁵ The program conducts training sessions for individuals who wish to be trained in ASD care. Many countries have recognized TEACHH as a starting point for their autistic

⁵² "Individualized Education Plan: An IEP Overview". 2016. *Child-Autism-Parent-Cafe.Com*. <http://www.child-autism-parent-cafe.com/individualized-education-plan.html>.

⁵³ "Individualized Education Programs (Ieps) For Autism". 2016. *Webmd*. <http://www.webmd.com/brain/autism/individualized-education-programs-ieps-for-autism>.

⁵⁴ "SESI Schools Overview – Alternative Special Education Programs – SESI Schools". 2016. *Sesi-Schools.Com*. <http://www.sesi-schools.com/about/about-overview/>.

⁵⁵ "Welcome To The University Of North Carolina TEACCH Autism Program — TEACCH". 2016. *Teacch.Com*. <http://teacch.com/>.

programs. Programs like SESI and TEACHH create a great example of how to properly deal with education serves for ASD children because they cater to any level of the spectrum and allow aid to be given as needed.

It is true that the services offered in the United States are not yet close to where they should be, but government support has given autism publicity and many organizations reason to pursue research and development in this health sector. President Barack Obama proclaimed “Thanks to the Affordable Care Act, insurers can no longer deny coverage to people because they have autism, and new plans must cover preventive services -- including autism and developmental screenings -- at no out-of-pocket cost to parents.”⁵⁶ With formal support given, the United States can now appropriately address the problem as a major concern and not just a few unfortunate mishaps. The proclamation continues, “NOW, THEREFORE, I, BARACK OBAMA, [...] hereby proclaim April 2, 2014, World Autism Awareness Day.”⁵⁷ Obama’s proclamation serves to reinforce and affirm the United States’ support of the United Nation’s day dedicated to autism awareness. Additionally “The Individuals with Disabilities Education Act (IDEA) is a federal law that requires that all children suspected of having a disability be evaluated without cost to families to determine if they have a disability and are eligible for services under IDEA.”⁵⁸ In 2014 the Achieving a Better Life Experience Act was signed into law in the United States. The 2014 Autism Speaks Report notes that this act “is widely considered the most significant disability-related legislation since the Americans with Disabilities Act (ADA) of 1990.”⁵⁹ The act allows individuals with disabilities to create tax preferred saving accounts while also receiving aid from other medical benefits. The implementation of these acts ensures no child is stripped of his/her rights to proper and meaningful development.

⁵⁶ The White House,. 2016. *Presidential Proclamation -- World Autism Awareness Day, 2014*. <https://www.whitehouse.gov/the-press-office/2014/04/01/presidential-proclamation-world-autism-awareness-day-2014>.

⁵⁷ (The White House 2016)

⁵⁸ Lee, Andrew M.I. 2014. "How IDEA Protects You And Your Child". *Understood.Org*. <https://www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/how-idea-protects-you-and-your-child>.

⁵⁹ *2014 Annual Report*. 2014. Ebook. 1st ed. <https://www.autismspeaks.org/about-us/annual-reports>.

Conclusion

Autism is not a disease to be afraid of; it is a disease to embrace. History has revealed the mistreatment and misdiagnosis of children with Autism Spectrum Disorder and the unfortunate truth is that mistreatment still exists in all regions of the world. The ignorance of governments and communities has made it difficult prohibited the human right of health to be fulfilled.

Currently, researchers have provided data and statistics surrounding symptoms and diagnosis. Organizations have done research to create accurate typologies and diagnostics, and some research has explored various causes of autism, and communities of professionals have started creating treatment plans inclusive of early childhood screening, observational diagnosis, and independent education plans. Research and case studies have exemplified the importance of detection and intervention at a young age, the early development stages of childhood. Addressing this disorder late in life can result in the formation of further social and mental issues. It is clear that parents, family, and society play a large role in combating the symptoms of this disorder. Organizations are working to provide additional support for parents.

The United States seems to be doing well in the area of communication and resources. The Center for Disease Control, Autism Speaks, and various other small organizations provide online resources for parents and physicians to access at any time. Despite these efforts there are still extensive gaps of knowledge and a limitless need for more research.

In Switzerland this issue is not just an issue of the ASD system but it is an issue of the overall education and diagnostic systems. Autisme Genève lists one solution as “put [ting] an end to segregation.” If the government chooses to recognize autism as a pressing and multifaceted issue, then reformation of the system will begin.

The International community has recognized autism through World Autism Day and some countries have seen positive improvement in their autism education programs. It seems that some organizations have begun referencing the successful models created in certain regions,

trying to implement them in their own country. However, without formal government support it is nearly impossible to appropriately and effectively implement certain programs.

Internationally, autism is another mental disorder that has been wrongfully unnoticed. If countries and organizations like the United Nations aim to address human rights issues they must stop mentioning issues and instead take action. While World Autism Awareness Day is a nice tribute, the international community needs to show their support in the form of policy making and active communication with autistic individuals. The next step is to combat international autism illiteracy.

Recommendations: for the advancement of autism

In the future human rights goals must be met. There must be increased screening for children of all ages. Training and education programs must be implemented for teachers, parents, physicians, and diagnostic specialists. Governments must increase their support for autism, and education practices must be reformed to include disabled children instead of exiling them to a separate school- mainstreaming. Data collection must increase so prevalence rates and tracking can be properly recorded and analyzed. Finally, there must be a movement to increased awareness and information on ASD in small and large communities around the world to reduce stigmatization, and mental health programs should be enforced in ALL health care systems.

References

2014 Annual Report. 2014. Ebook. 1st ed. <https://www.autismspeaks.org/about-us/annual-reports>.

"A Child With Autism Can Get Their Needs Met... From Preschool To Adult Services." 2016. *Child-Autism-Parent-Cafe.Com*. <http://www.child-autism-parent-cafe.com/>.

"ABA Resources: What Is ABA?" 2016. *Center For Autism And Related Disorders*. <http://www.centerforautism.com/aba-therapy.aspx>.

"About SPAN | Statewide Parent Advocacy Network, Inc.". 2016. *Spanadvocacy.Org*. <http://www.spanadvocacy.org/content/about-span>.

- "All About The IEP | Center For Parent Information And Resources". 2016. *Parentcenterhub.Org*. <http://www.parentcenterhub.org/repository/iep/>.
- ALTERNATIVE REPORT SUBMITTED BY 'AUTISME GENÈVE' TO THE COMMITTEE ON THE RIGHTS OF THE CHILD IN CONNECTION WITH THE REVIEW OF SWITZERLAND'S SECOND PERIODIC REPORT TO THE COMMITTEE ON THE RIGHTS OF THE CHILD*. 2016. Ebook. 1st ed. <http://www.autisme-ge.ch>.
- American dance Therapy Association,. 2014. *Dance/Movement Therapy & Autism: Dances Of Relationship*. Video. https://www.youtube.com/watch?time_continue=3&v=65DLHYrHlIM.
- "Autism". 2016. *Aap.Org*. <https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx>.
- "Autisme Genève". 2015. *Autisme-Ge.Ch*. <http://autisme-ge.ch/>.
- Baker, Jeffrey P. 2008. "Mercury, Vaccines, And Autism". *Am J Public Health* 98 (2): 244-253. doi:10.2105/ajph.2007.113159.
- Barman, Yvette and Marie-Jeanne Accietto. 2016. Independent Research Study of the Education Systems for Autism in Switzerland Interview by Savannah Dysard. In person. Autisme Genève Office.
- Carpenter, Laura. 2013. *DSM5 AUTISM SPECTRUM DISORDER*. Ebook. 1st ed. American Psychiatric Association. [https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5\(ASD.Guidelines\)Feb2013.pdf](https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5(ASD.Guidelines)Feb2013.pdf).
- "Dance/Movement Therapy And Autism". 2016. *Psychology Today*. <https://www.psychologytoday.com/blog/meaning-in-motion/201404/dancemovement-therapy-and-autism>.
- Dysard, Savannah. LetterGiuliana Galli Carminati to . 2016. "Independent Study Project". Email.
- Dysard, Savannah. LetterMyriam Alizo to . 2016. "Independent Study Project". Email.
- "Facts About Asds". 2016. *CDC - Facts About Autism Spectrum Disorders - NCBDDD*. <http://www.cdc.gov/ncbddd/autism/data.html>.
- "Final Update Summary: Autism Spectrum Disorder In Young Children: Screening - US Preventive Services Task Force". 2016. *Uspreventiveservicestaskforce.Org*. <http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/autism-spectrum-disorder-in-young-children-screening>.
- Gennai Deveaud, Tamaé. 2016. Independent Research Study of the Education Systems for Autism in Switzerland. Interview by Savannah Dysard. In Person. Nyon Roulotte.
- Gillberg, Christopher, Elisabeth Fernell, and Helen Minnis. 2013. "Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations". *The Scientific World Journal* 2013: 1-2. doi:10.1155/2013/710570.

- Halladay, Alycia. 2016. "What Is Epigenetics, And What Does It Have To Do With Autism?". *Autism Speaks*. <https://www.autismspeaks.org/node/123021>.
- "Individualized Education Plan: An IEP Overview". 2016. *Child-Autism-Parent-Cafe.Com*. <http://www.child-autism-parent-cafe.com/individualized-education-plan.html>.
- "Individualized Education Programs (Ieps) For Autism". 2016. *Webmd*. <http://www.webmd.com/brain/autism/individualized-education-programs-ieps-for-autism>.
- Katirae, Layla. 2015. "Will My Child Be Born Autistic If I Eat Gmos? A Scientist'S View". *Genetic Literacy Project*. <https://www.geneticliteracyproject.org/2015/01/05/will-my-child-be-born-autistic-if-i-eat-gmos-a-scientists-view/>.
- Lee, Andrew M.I. 2014. "How IDEA Protects You And Your Child". *Understood.Org*. <https://www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/how-idea-protects-you-and-your-child>.
- Madsen, Kreesten Meldgaard, Anders Hviid, Mogens Vestergaard, Diana Schendel, Jan Wohlfahrt, Poul Thorsen, Jørn Olsen, and Mads Melbye. 2002. "A Population-Based Study Of Measles, Mumps, And Rubella Vaccination And Autism". *New England Journal Of Medicine* 347 (19): 1477-1482. doi:10.1056/nejmoa021134.
- "NIMH » Autism Spectrum Disorder". 2015. *Nimh.Nih.Gov*. <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>.
- Ozonoff, S., G. S. Young, A. Carter, D. Messinger, N. Yirmiya, L. Zwaigenbaum, and S. Bryson et al. 2011. "Recurrence Risk For Autism Spectrum Disorders: A Baby Siblings Research Consortium Study". *PEDIATRICS*. doi:10.1542/peds.2010-2825.
- Palmer RF, et al. 2016. "Proximity To Point Sources Of Environmental Mercury Release As A Predictor Of Autism Prevalence. - Pubmed - NCBI". *Ncbi.Nlm.Nih.Gov*. <http://www.ncbi.nlm.nih.gov/pubmed/18353703>.
- Pringle, Beverly A., Lisa J. Colpe, Stephen J. Blumberg, Rosa M. Avila, and Michael D. Kogan. 2012. *Diagnostic History And Treatment Of School-Aged Children With Autism Spectrum Disorder And Special Health Care Needs*. Ebook. 1st ed. CDC. <http://www.cdc.gov/nchs/data/databriefs/db97.pdf>.
- "SESI Schools Overview – Alternative Special Education Programs – SESI Schools". 2016. *Sesi-Schools.Com*. <http://www.sesi-schools.com/about/about-overview/>.
- Sharp, William G., Rashelle C. Berry, Courtney McCracken, Nadrat N. Nuhu, Elizabeth Marvel, Celine A. Saulnier, Ami Klin, Warren Jones, and David L. Jaquess. 2013. "Feeding Problems And Nutrient Intake In Children With Autism Spectrum Disorders: A Meta-Analysis And Comprehensive Review Of The Literature". *J Autism Dev Disord* 43 (9): 2159-2173. doi:10.1007/s10803-013-1771-5.
- "The Human Brain Project - Human Brain Project". 2016. *Humanbrainproject.Eu*. <https://www.humanbrainproject.eu/>.

The White House,. 2016. *Presidential Proclamation -- World Autism Awareness Day, 2014*.
<https://www.whitehouse.gov/the-press-office/2014/04/01/presidential-proclamation-world-autism-awareness-day-2014>.

"What Is Autism? What Is Autism Spectrum Disorder?". 2016. *Youtube*.
<https://www.youtube.com/watch?v=Flcy0XK5j3I&nohtml5=False>.

"Welcome To The University Of North Carolina TEACCH Autism Program — TEACCH".
2016. Teacch.Com. <http://teacch.com/>.