

Autism Minnesota from the 1800's to Present; The Roots of Autistic and Disabled Advocacy

*“Our great democracy can be measured best by what it does for the least of its little citizens... With rare exception, the provisions we have made ... are barbaric.”*¹ - Luther W. Youngdahl, former governor of Minnesota, at the first national convention of the National Association of Parents and Friends of Mentally Retarded Children, September 30, 1950.

In a packed auditorium in Minneapolis, Minnesota on September 30, 1950, a dent was made in the communication barrier between disabled Americans and the general public by then governor of Minnesota, Luther W. Youngdahl. At the time, Autistic and other individuals seen as “retarded” were often not allowed in public schools, put in homes, and forgotten about. Prior to 1970, it is estimated that one million children were completely excluded from public schools in the United States; a mere 20% were allowed to attend, and it is certain the education they received was sub par.² Beginning in the 1950's, when disabled awareness and advocacy began to flourish in the United States, and continuing onto today, when the federal government has laws guaranteeing any child who needs special education to receive it, Autistic Advocacy has truly helped to ensure the wellbeing and care of American citizens with Autism and other disabilities. Without

¹ Author Unknown. “ARC's Walk Through Time.” ARC Carver-Hennepin. March 8, 2005.
<<http://www.archennepincarver.org/about/history.html>>
AND

Anonymous. “A History of the National Association for Retarded Children, Inc.” ARC. March 9, 2005.
<<http://www.thearc.org/history/anonymou.htm>>

² Allyn & Bacon. “Inclusive Education, an Introduction.” Microsoft PowerPoint Presentation. 2004.

this movement, and the efforts of such advocates, the social situation for Americans with Autism would be much like it was over fifty years ago.

The Autistic movement begins jointly with the disabled rights movement, which began as early as the mid-1800's with the foundation of the American Asylum for the Education of the Deaf and Dumb, a school specifically for students with hearing problems and mental illnesses.³ For 1817, this was as activist a statement as ever – disabled people deserved somewhere to belong. Unfortunately, this still meant such children had no place in a private home. Specific mental illnesses were largely unnamed, and children who showed signs of mental retardation or other affliction were simply referred to as “dumb.” In 1832, the New England Asylum for the Blind was founded, and further attributed to the foundations of the disabled rights movement.⁴ In the early days of disabled rights movements, progress came in the form of education and education reform. Slowly, schools began to realize the need for specialized education, though official legislation towards this would not be passed until the 1970's.

For years, Autism was referred to as a form of schizophrenia, caused by so-called “refrigerator mothers”⁵ - a disease that stole the personalities and development of new mothers' babies, a disease that would land a child a life-sentence in a psychiatric ward or institution for the rest of their lives. Autism, in all its many variations, was generally grouped with mental retardation and “the dumb.” In 1943, psychiatrist Leo Kanner observed eleven children who all displayed signs of Autism who had mistakenly been

³ Luckner, John E., Ed. D.. “Issues in Deafness.” March 13, 2005.
<<http://www.nclid.unco.edu/DeafIssues.htm>>

⁴ Allyn & Bacon. “Inclusive Education, an Introduction.” Microsoft PowerPoint Presentation. 2004.

⁵ Gallagher, Diane and Joyce Santo. Class Notes, Taken by Diane Bell. June 2004.

diagnosed with mental retardation or other behavioral problems.^{6 7} He labeled these children Autistic, a term that had been coined in 1911 by psychiatrist Eugen Bleuler, the same man who named schizophrenia. The term Autism comes from the Greek word “autos” – meaning self.⁸ It was then, at John Hopkins hospital in Baltimore that the Autistic spectrum gained any recognition. Through his and others’ work and the increasing level of communication between peoples with disabilities, the level of public acceptance, understanding, and finally, embracement has grown to a level even Kanner himself may never have expected.

Before the discoveries of both Leo Kanner and Hans Asperger, the Austrian pediatrician who, in 1944, first put a name to the variation of Autism now called Asperger’s Syndrome,⁹ Autism was thought to be the effects of frigid mothering. Imagine being the mother of an Autistic child in Saint Paul before the 1970’s; you have no idea what is wrong with your child, and everyone blames the disorder on you, and the general consensus is this could all have been prevented, if only you were a better mother.¹⁰ It’s really no wonder why so many Autistic children were institutionalized in Minnesota before the 1950’s and 60’s; there was really little to no other option in these parents’ minds. Since there was truly no public awareness about Autism, nor many doctors willing to even think about the idea of rehabilitation (much less acceptance and embracement of

⁶ Phillips, Kevin. “The History of Autism.” March 13, 2005.

<<http://www.angelfire.com/amiga/aut/authist.html>>

⁷ De Mello, Anna Maria S.R.. “Autistic Disturbances of Affective Contact – Leo Kanner’s Case Histories.” March 1, 2005. <<http://www.ama.org.br/kannereng12.htm>>

⁸ Author Not Listed. “Information Sheet for Secondary School and College Students.” National Autistic Society. March 8, 2005. <<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=299&a=3358&view=print>>

⁹ Aspies For Freedom. “Hans Asperger.” March 13, 2005.

<http://www.aspiesforfreedom.org/wiki/index.php/Hans_Aasperger>

¹⁰ PT Staff. “Films: What to Watch.” Psychology Today. October 28, 2004.

<<http://cms.psychologytoday.com/articles/pto-20041018-000002.html>>

the individual), parents were often trapped into the idea that there was no hope for their child.

Much more is known about Autism today than sixty years, and thankfully the atmosphere between Autistics and neurotypicals (NTs) has become much clearer. The term “neurotypical” is a term generated by Autistic Advocates in response to curation-based foundations which believe Autism is a disease like cancer or AIDs that needs to be cured. The standpoint taken by such advocates is based on the idea that the worth of a person with Autism is equal to the worth a person without Autism; a neurotypical. This is to say that though there are definite differences between NTs and Autistics, both are perfectly normal and should be accepted as such. Advocates of this moral persuasion have started such groups as Advocating Change Together, or ACT, which is based in Minnesota,¹¹ and the Parent Advocacy Coalition for Educational Rights which provides trained advocates to sit in on meetings and attend discussions about children receiving special education who need professional support against an adversary (sadly, this is often the school itself).¹²

One of the more controversial aspects of Autistic Advocates is just how one should refer to a person on the spectrum – person with Autism or Autistic person? Since the movement is about embracing and accepting Autism, many choose to refer to themselves as Autistics, rather than persons with Autism. It is an interesting way of telling the rest of the world they accept and embrace their Autism as an integral part of their person.

¹¹ Advocating Change Together. “Accomplishments.” March 12, 2005.
<http://www.selfadvocacy.com/aboutact_accomplishments.htm>

¹² Goldberg, Paula F.. PACER Center. <www.pacer.org>

Scientists have recently come out against the idea that Autism is caused by the mercury in childhood vaccinations. This theory was, and still is, quite popular among curation-based groups such as The Cure Autism Now! Foundation (CAN),¹³ AutismSpeaks,¹⁴ and others, as it attempts to dismiss the idea that Autism is genetic (and thus curable, without genetic modification or selective abortion). The guilty agent in such vaccines is a Mercury derivative called Thimerosal, which was approved by the FDA to be used in multiple Hepatitis and Influenza vaccines in the mid- to late-90's.¹⁵ In 1997, the FDA passed the Food and Drug Administration Modernization Act, or FDAMA, which included a study into the effects of vaccines with Thimerosal. In this study, the FDA found very few incidents in which a receiver of a Thimerosal vaccine had an adverse reaction, and those who did were mostly cases of sensitivity reactions (raised spots near needle puncture, etc).¹⁶ This is not to say that Thimerosal cannot cause Autism, but it does suggest the majority of Autism diagnoses are results of genetics. Since the majority of cases of Autism are diagnosed no sooner than eighteen months of age, it is hard to tell if Thimerosal laden vaccines are a cause, or simply a coincidence.

While research into the connections between Thimerosal and Autism is vital, it is also important to look at history, and the steps so many Autistics have taken to communicate their need for civil rights to the general public. In the past, Autistic children have been used repeatedly against their will in studies of Autism. To test anyone against their will goes against most commonly held morals, as does leading a child to believe he

¹³ Cure Autism Now! "Frequently Asked Questions about Autism." March 1, 2005.
<<http://www.cureautismnow.org/kb/subcat/3208.jsp>>

¹⁴ Wright, Bob and Suzanne. "Autism Speaks: It's Time to Listen." February 20, 2005.
<www.autismspeaks.org>

¹⁵ US Food and Drug Administration. "Thimerosal in Vaccines." March 5, 2005.
<<http://www.fda.gov/cber/vaccine/thimerosal.htm>>

¹⁶ US Food and Drug Administration. "Thimerosal in Vaccines." March 5, 2005.
<<http://www.fda.gov/cber/vaccine/thimerosal.htm>>

or she is abnormal and undesirable. Why, then, does it seem that in American culture today, this is an okay standpoint when the child is Autistic?

To combat foundations and groups who believe Autism is a curable disorder (or a disorder at all), many Autistic Advocates have become extremely vocal in the past twenty years or so. Take, for example, Temple Grandin, the author of multiple books and holder of a doctorate degree. Diagnosed with an Autism-like disorder as a child, she was not expected to become something great. She spent the majority of her childhood in boarding schools, and it seemed as if the world was against her. She persevered against it all, though, and is now a world-renowned expert on something she calls the “squeeze machine” – a machine that provides bovines with high levels of soothing tactile stimulation (something she craved as a child) before they are slaughtered. She travels around the country speaking on these machines and tries to get others to consider how the animal feels.¹⁷ Her research has also helped to dispel the myth regarding Autistics as cold or heartless individuals – simply another result of miscommunication and thus vast misunderstanding.

Since their beginning, all civil rights groups had strong opposition, and the disabled rights movement was never exempt from this fact. A group which founders called the American Eugenics Movement, which would later be a great resource to Adolf Hitler’s Third Reich, published an exhibit in 1926 which spoke of the need to “cure” mental illness. This exhibit features the slogan “*Some people are born to be a burden on the rest. Learn about heredity. You can help to correct these problems.*”¹⁸ (Image of exhibit in Appendix). While this idea sounds quite far off from modern reality, one only

¹⁷ Grandin, Temple. EMERGENCE: Labeled Autistic. New York: Warner Books. 1986.

¹⁸ Author Not Listed. “Then and Now.” March 2, 2005.
<<http://www.autistics.org/library/thenandnow.html>>

has to look from the standpoint of an Autistic adult to see this is not the case. With the prevalence of organizations based on the belief that Autism should be cured, is this sentiment truly gone, or only worded with a better sense of political correctness?

Unfortunately, as with any other minority group, Autistics still face many hardships as a direct result of their communication and interaction with NTs. In a school setting, this is much more apparent. Even in a kindergarten class, there are social lines being drawn between the “cool” and the “uncool;” the accepted and the ridiculed.¹⁹ Just as lifelong institutionalization that was common 50 years ago is now seen as wrong, the mockery and closed-minded sociological nature of our society is just as harmful to the bearers.

Following the beginning of true social awareness and equal rights movements that took place in the 1960's and very early 70's during the African American Civil Rights Movement and Vietnam war protester mentality of equality, the United States Government passed what is now known as the Americans with Disabilities Act of 1973. This Act was one of the first solid steps in the promotion of disabled awareness, and thus the door was open for communication between the disabled and non-disabled. In Minnesota, the ADA brought entirely new opportunities to Autistics, because no longer were companies allowed to discriminate against applicants or employees, based on their disabilities. Soon after the ADA was enacted, the United States passed the first Individuals with Disabilities Education Act, or IDEA. The IDEA guarantees students an appropriate public education, even if this means that the child will require some special education.

¹⁹ Imbrone, Katy. Personal Observation. Sheridan Hills Elementary. Richfield, MN. February 22, 2005.

A child with a recognized need for special education is set up with either a 504 plan, or an Individualized Education Plan (IEP), which states accommodations and modifications necessary for the student to be successful. The 504 plan differs from an IEP in that IEPs are seen as long-term, and must be renewed annually until the student graduates, while a 504 plan can be temporary.²⁰ This seemingly small change was, in fact, an enormous step in disabled and Autistic Advocacy, as it recognized that, though they may be different from their peers, disabled children (including Autistic children) deserve an appropriate education.

With any law attempting to almost completely reverse a social trend, the ADA had some large obstacles to overcome in the first few years. The ADA has five titles, which are, numerically; employment, state and local government activities, public transportation, public accommodations, and telecommunications relay services. These five titles decreed, in depth, exactly how society should be run concerning the welfare of disabled peoples. The first act dealt mostly with issues of discrimination at the workplace, and since this is an extremely “case-by-case” issue (meaning that, even within the same workplace, the attitudes towards disabled co-workers can and do vary greatly). The following acts decree specifications as to such things as ramps on buildings, door sizes in public areas, sidewalks, etc.²¹ Again, this change, brought on by the vocalization of their needs from the Autistic and disabled community, helped to further the acceptance so deserved.

²⁰ PACER Advocates. “IDEA and the Individualized Education Plan (IEP).” PACER Center Workshop. PACER, Bloomington, MN. March 10, 2005.

²¹ US Department of Justice. “A Guide to Disability Rights Laws” March 1, 2005.
<<http://www.usdoj.gov/crt/ada/cguide.htm>>

When asked about Autistic Advocacy in a survey, many Autistic adults responded with hope for the future, but also a word of caution. “John Doe,” who wishes not to be identified with their full name, states eloquently *“I believe advocacy starts at home. Until we can remove the public perception of us as "impaired", "damaged", "mentally disabled", "kinda like retards", or what have you, we're not going to have much success changing public policy... We must learn to use emotional language that they can understand, to demand respect, even to be "angry". Neurotypicals have a belief, and a need to believe, that being a 'person' means being like them, and will not see us as fully human until they can identify with us.”*²²

Back in 1943, would Leo Kanner even imagine what is going on in Minnesota, and the United States today? Could he have possibly envisioned children diagnosed with the disorder he identified, out advocating for their own equal treatment and rights? Today, the intense efforts of the United States government, pushed by the civil rights movement and the Autistic and disabled coming-out movement of the seventies and eighties are finally paying off. Today, the Autistic Advocacy movement is stronger than ever, and is growing in numbers of participants. Similar to the African American Civil Rights Movement in plight, Autistic persons are demanding to be heard as individuals, and be given the rights they, as integral members of our societies. Perhaps some day the intense efforts of such advocates will put an end to the oppressive nature of some members of the same society. Autistic Advocacy has come from a group of ninety parents in a crowded auditorium in Minneapolis to a million-member group of individuals voicing their needs for equal treatment, and their right as human beings to be embraced for who they are in our society.

²² “John Doe.” Personal Interview via Email. March, 2005.

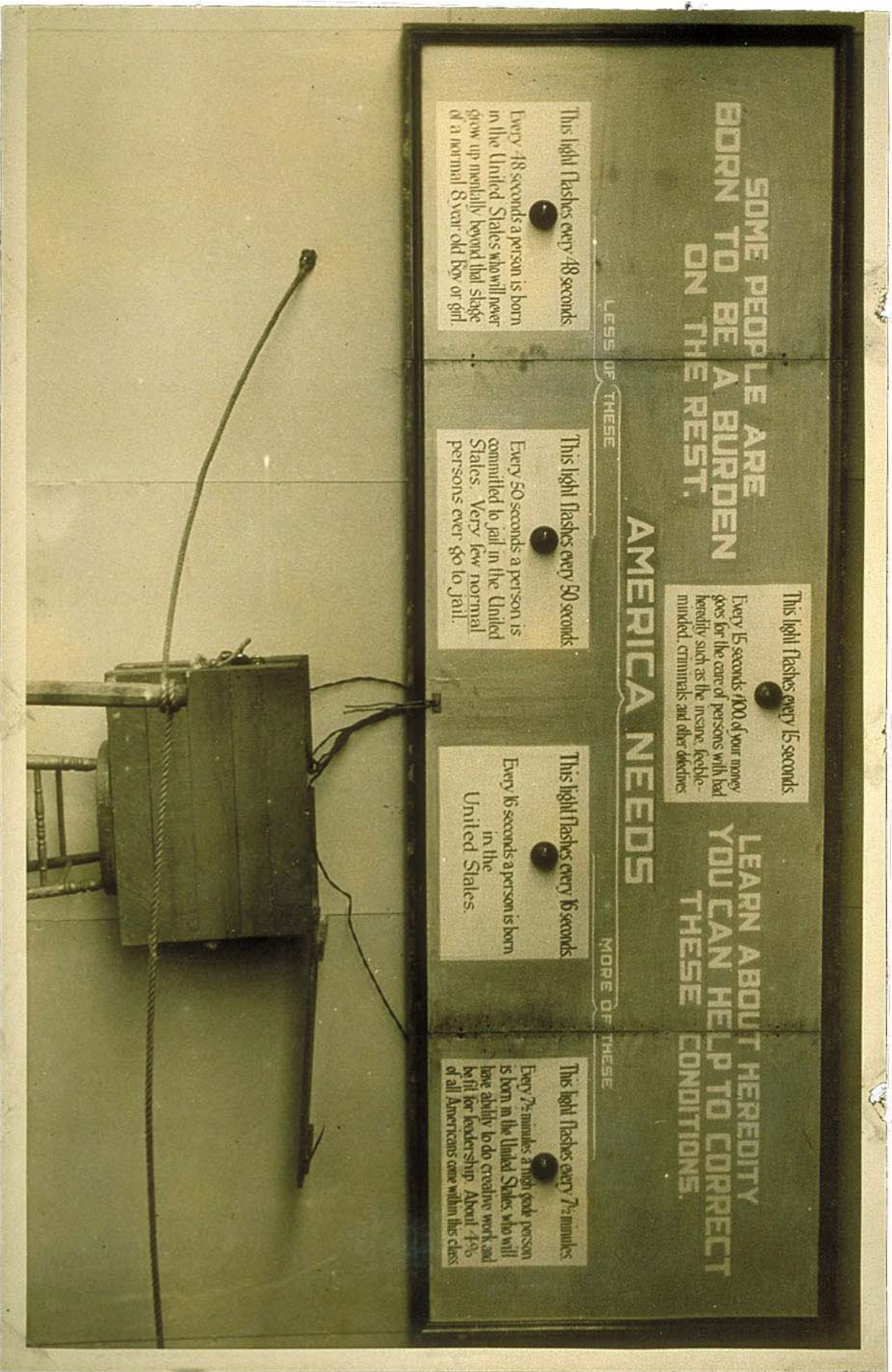


Image courtesy of Autistics.org and the American Philosophical Society.

This is a photograph of the American Eugenics Movement's 1926 exhibit of hereditary diseases and mental illness. See page 6 for explanation.