

Insights from

**AUTISM:  
A SOCIAL  
AND  
MEDICAL  
HISTORY**

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# First, a word about history...

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History is always written from a particular perspective. You could write a history of autism from the perspective of medicine, psychiatry, psychology, occupational therapy, genetics, education, or parenting. Each discipline has its own way of looking at the world, its own vocabulary. Each is based on a set of ideas that exert control over how it perceives the same evidence.

But in these stories, people with autism themselves disappear—because their own perspectives and experiences are not included.

In my work, I have tried to gather information from multiple viewpoints, but always with the lives of people with autism at the core of my analysis.

Also, as other historians of disability have shown, how we define and respond to human differences and illnesses is largely determined by culture, including economics. For that reason, I have also strived to explain changes affecting people with autism as they relate to larger economic and cultural changes.

# Ideas and their impact

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*The history of autism is not a story of continual progress toward truth: it is largely a story about how ideas, whether these are based on beliefs or evidence, affect practices. These changing ideas have had a strong impact on people with autism, their families, and society as a whole, as well as on professional practice.*

# An autism timeline

- For most of human history, there was no special word for autism, and so there were no special ideas about autistic people.
- There was no formal education, and so no one had “special educational needs.”
- There was no research into child development or paediatric health care, so divergent trajectories were only noticed by parents, in comparison to children they actually knew.



# Autistic people before “autism”

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- That doesn't mean that people with autism had an easy life.
- Children and adults with intellectual difficulties (with or without autism) had poor survival rates. There is a higher rate of seizure disorders and some other medical problems among people with autism, and these went untreated.
- Child abuse was legal and common, and we know that children seen as “different” or whose behaviour is challenging are more frequently abused, even today.

# An autism timeline

- By the Greco-Roman era, “normalcy” was starting to be defined, through descriptions of ideal types. Those who did not approach the ideal were treated differently, and sometimes even killed.
- Other explanations for difference could directly cause harm.
- Some religions saw intellectual difficulties, unusual movements or behaviours, or seizures as marks of “impurity” or demonic possession. People with autism may have been abused, killed or shunned.
- Folk beliefs, like the “changeling” myth that recurs in autism history, were also sometimes damaging.



# An adult with “autism” in the Middle Ages



- Abandoned as a boy at the Wearmouth monastery in Sunderland (north east England)
- Non-verbal, taught by monks to use some speech and their own sign language
- Lived separately from the monks on the monastery grounds
- Like others living at the monastery, probably engaged in repetitive farming, fishing and cleaning tasks
- Few people achieved literacy at this time, and life patterns and work were usually predictable—especially at Wearmouth

# An autism timeline: 18<sup>th</sup> and 19<sup>th</sup> century

- Enlightenment era: Beginnings of modern medicine
- Asylum system: first for adults seen as mad or “feebleminded,” then for children as well; expands rapidly
- Victorian era: classification of human “types” and diseases, science and pseudoscience
- Changing economic systems, changing families



# An “autistic” child in the 19<sup>th</sup> century: Ralph Sedgwick

- Admitted to Great Ormond Street Hospital for Children in 1877, age 2 ½
- Symptoms described included developmental delay, lack of speech, gaze/attention difference, repetitive behaviours, feeding and bowel problems
- Supernatural and medical ideas
- Died 1878, cause unknown
- Medical care, home services, education unavailable for typical children, few asylums open to children



# An autism timeline: Early 20<sup>th</sup> century

The application of “science” to child development:

- Developmental data and charts
- IQ testing
- Psychology and psychiatry
- Child Guidance movement applies these to “prevention, with focus on mothers”
- Socio-economic imperatives: eugenics aimed at cost-savings and getting more people into the workforce, Child Guidance movement aimed at increasing social control through “scientific” parenting



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# An autism timeline: 20<sup>th</sup> century

- Autism named by Leo Kanner in the US in 1943; Hans Asperger in Germany 1944, both using terminology borrowed from Bleuler
- Until 1970s, synonymous with “childhood schizophrenia”
- Freudian ideas applied to autism: Bruno Bettelheim, Melanie Klein, Margaret Mahler, Francis Tustin, Erich Fromm, Jacques Lacan... *almost all* psychologists and psychiatrists
- Psychological therapies for parents and lifelong institutionalisation are standard for less able people; more able people often misdiagnosed and mistreated, or caught in other institutional matrices i.e. sheltered workshop system, care homes, prisons, psychological therapies

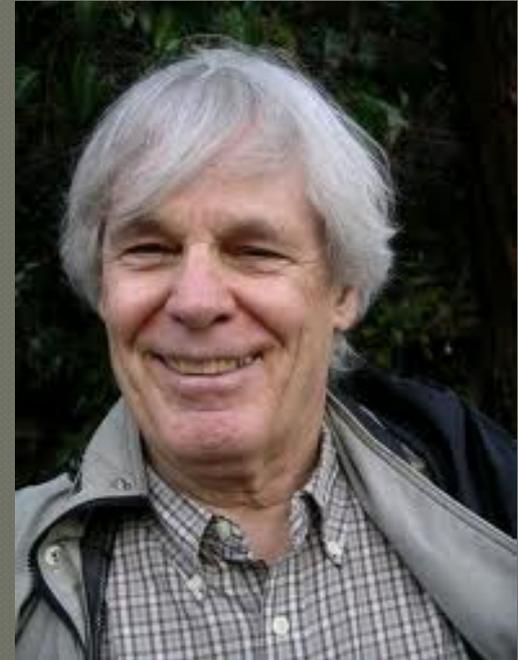


# An “autistic” person in 1944: Ted Chabasinski

In 1944, six-year-old Ted Chabasinski was diagnosed with “childhood schizophrenia” and placed in a mental hospital. He was given repeated shock treatments by Dr Lauretta Bender. He recalls:

*“On the mornings when I was going to get the shock treatment, I didn’t get any breakfast, so I knew what was going to happen. On those mornings, while the other children sang obediently, I would cry without stopping.”*

He was also physically and sexually abused. Chabasinski spent most of his childhood in mental hospitals.



# An autism timeline: 20<sup>th</sup> century

- In 1962, Bernard Rimland published the first collection of evidence suggesting that autism had a biological cause.
- Ivar Lovaas applied behaviourist theories of autism, starting in the 1960s; published in 1970s and 1980s
- In most countries, there was no right to education for children with disabilities until the 1970s or later. In many, there still is not. Segregated education for children with autism remains common today—including in the Netherlands.

# An autism timeline: 20<sup>th</sup> century

- The Disability Rights Movement, including the anti-psychiatry/psychiatric survivors movement, in which Ted Chabasinski was a pioneer, and People First, emerged in the 1970s
- Deinstitutionalisation also started in the 1970s. This is incomplete: some autistic people are still institutionalised, and where large institutions closed, they have often been replaced with smaller or virtual institutions, including therapeutic parenting.



# A person with autism today

- Ian was born in 1990 in the US, educated in US and UK
- Delayed development, communication problems and atypical behaviour, first diagnosed with PDD, then autism.
- Medication, diets, supplements: cure mentality
- Special education: Freudian ideas persisted alongside behaviourism, CBT, TEACCH, physical, speech and occupational therapy: Normalisation and control.
- Despite it all, Ian eventually completed school and continued on to further and higher education
- Occupied but unemployed
- Open and positive about diagnosis, aware of disability rights movement and autism self-advocacy/activism





# Autism today

- Post-1980, autism increasingly medicalised
- The Combating Autism Act (2006) has accelerated this process by funding large-scale research
- Drug companies able to use “fast track” process, CAA and mega-charity Autism Speaks to develop profitable “treatments” that control behaviour without considering its cause
- Strong drive towards genetic research, and earlier and prenatal diagnosis: eugenics again?
- Diagnostic rate at least 1 in 100, 1 in 68 according to the Centres for Disease Control in the US—and higher rates have been reported. Broader diagnostic category, now catches more able and also those with additional conditions.

Tell Congress:

**#StopCombatingMe**

A #boycottAutismSpeaks



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# Autism today

- At the same time, however, the voices of people with autism themselves are increasingly being heard, through self-advocacy and collective action
- Most adults with autism highlight the importance of sensory-perceptual differences rather than the behaviours currently used to diagnose autism
- Sensory-perceptual differences may underlie atypical developmental and behaviour
- But there is strong resistance within the “autism industry” to listening...
- Schools and workplaces have also changed in ways that produce increased distress and disability

# A social model of autism

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Disability studies offers an alternative to the prevalent medical model of autism, and to older narratives: the social model.

The social model separates **impairment**—physical or mental differences that may limit certain activities—from disability. It defines **disability** as a form of social oppression: the ways in which society limits or excludes (disables) people who have or are perceived to have an impairment.

The social model asks us to look at how disability is socially constructed. With autism, that means asking why we have decided that certain traits are abnormal, and examining how society may disable people who have autistic traits.

What is the function of the idea of “normalcy,” and where does it come from?

# What is “normal”?

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Diagnosis of autism is extremely subjective.

Ask yourself: When does a special interest become an “obsession”? When is behaviour “repetitive” or “disruptive”? What is a “normal” pattern of development? What is a “normal” configuration of mirror neurons?

Almost everything we believe about autism is based on comparing one set of people who are supposedly “abnormal” to another set of people who are supposedly “normal.”

These definitions position at least 1 in 100 people as damaged goods. This devaluation creates both a pressure-filled agenda and an autism industry that promises to fulfil it: it declares that these people will only have value if made “normal.”

# Autism and neurodiversity

- An alternative concept is neurodiversity: the idea that as with skin colour, gender, sexuality and cultural characteristics, there is more than one kind of “normal” brain—and that as with biodiversity, this may be important for our survival as a species.
- First named by Judy Singer, a woman with autism, this is a concept with resonance beyond autism. It fits within the discourse about bodily difference in Disability Studies and the Disabled Peoples Movement.



# Autism and neurodiversity

The medical model is not as evidence-based as it may seem: it still measures people against an arbitrary norm and assumes that “normal” is always right and best.

The spectre of genetic (de)selection, as is currently widely practiced regarding Down syndrome, makes understanding this even more important.

When we hold or act on assumptions and beliefs about what is “normal,” we only add to discomfort or difficulty experienced by people with autism that is due to actual impairment.

For people with autism, autistic behaviours *are* normal. We need to think carefully about forced normalisation: it damages and devalues people, and it doesn't work.



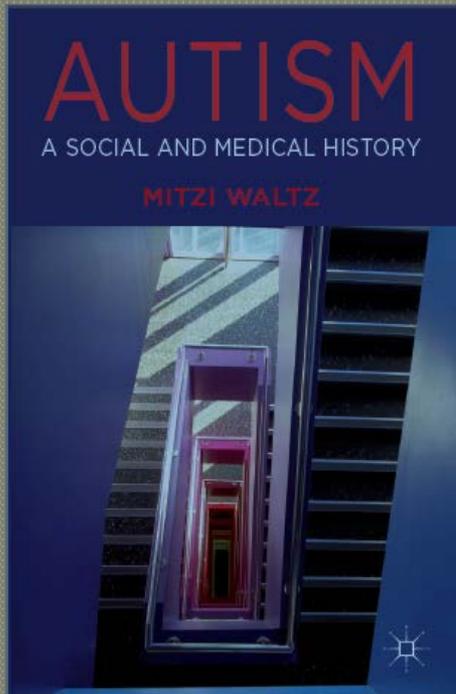
# Towards a social model of autism

A social model of autism asks us to examine what disables people with autism. Is it a set of atypical traits and behaviours that does this, or is it inflexible institutions like schools and workplaces, or social attitudes that do not accept and value difference?

It suggests that neurological diversity is simply a part of being human, not necessarily a problem.



# Book and contact details



**Autism: A Social and Medical History (2013)  
London: Palgrave Macmillan**

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