

# A history of early autistic space

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# Before ‘autism’

Ref.: Waltz, 2013; Silberman, 2015

- \* Survival for severely disabled was low. However, autistic traits such as superior pattern recognition would have had advantages in prehistoric societies (which were relatively uncomplicated and predictable).
- \* Folk beliefs, such as changelings, leading to torture and murder of children with disabilities, were pervasive for millennia.
- \* Late 19th/early 20th century: Psychology/psychiatry turned folk beliefs into ‘science’. ‘Degenerates’/ ‘defectives’ were now made to ‘disappear’.
- \* Term ‘autism’ first used by Eugene Bleuler in 1911 to describe one aspect of ‘schizophrenia’: *deliberate* escape from reality as a coping skill.
- \* Autism and ‘hospitalism’ (trauma): enduring confusion due to similar outward characteristics, reinforcing belief that autism is deliberate escape.

# Rise of parent narratives (1960/70s)

Ref.: Waltz, 2013; Silberman, 2015

- \* 1940s: Leo Kanner, Hans Asperger described autism in terms of case studies: one form of narrative. *It's been all about the narrative ever since.* Perspective of subjects being studied completely absent from narrative.
- \* Psychoanalysts (led by Melanie Klein) blamed 'refrigerator' mothers – a narrative that endured for decades (in France even now).
- \* As a reaction, parents started autism organisations (e.g. NAS in 1962) and developed an enduring mistrust of mainstream science, while still adopting a medical and pity/charity model of autism.
- \* Behaviourism/ABA: promise for people the psychoanalysts had written off as hopeless. But if child failed to be cured, parents were still blamed.

# Autism: permanent war of narratives

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- \* Kanner & Asperger: original pair of competing narratives
- \* Psychoanalytical vs. behaviourist narrative
- \* Parent narratives introduce new science (neurobiological causes) as well as lots of nonsense (antivaccine etc)
- \* Abysmally low standards of ethics and science (ref.: Dawson, 2004)
- \* *Where is the autistic narrative?*

# 1992: Parents vs autistics on Internet

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- \* Parents took to internet: St John's University AUTISM mailing list (founded by Ray Kopp, 1992). Parent- and treatment-oriented.
- \* Some autistics started to insert themselves into the discussion, but parents mostly used them as resources ('self-narrating zoo exhibits'). Communication between autistics was considered an annoying waste of bandwidth. (Sinclair, 1994)

# Reaction: autistic space

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- \* Fed up with being patronised, Autism Network International (Sinclair et al) started ANI-L in 1994, with hosting provided by Syracuse University. First online autistic space.
- \* In 1996, building on internet community, ANI organised Autreat, the first conference for and by autistics. Took idea of autistic space to 3D realm (a.k.a. ‘real life’).
- \* ‘Cousins’ – people with autism-like conditions – were also welcomed. Inclusive term: ACs (autistics and cousins).
- \* ISNT: the narrative on its head (Tisoncik, 1998)

# What is autistic space?

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- \* Shared by several autistic people
- \* Designed or adapted for autistic processing; values autistic ways of functioning
- \* Autistic people are in charge: *we* determine our own needs and how to meet them
- \* Higher chance to meet similar and/or compatible people
- \* Still difficulties: autistic people are not just different from NTs but also different from each other, causing incompatibilities

# Online autistic space

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- \* Text-based: avoids social and sensory processing and overload; slower pace gives plenty of time to think and react
- \* Both correspondence (mailing lists) and interactive (IRC)
- \* Self-selecting for literacy and ability to handle computers
- \* ‘Typing personality’
- \* Lack of facial expressions etc. is actually an advantage
- \* NTs tend to be rather socially disabled here!

# So what was *our* narrative?

Ref.: Singer (1998), Dekker (1998)

- \* Mutual emotional and practical support
- \* Self-advocacy
- \* Recognition of the reality of pervasive neurological differences
- \* Civil rights
- \* Appropriate services

# InLv

Ref.: Choisser, 1997; Singer, 1998

- \* Run by hand, on dial-up. First fully autistic-run, self-hosted Internet autism community.
- \* Neurodiversity
- \* Face blindness



# #asperger (IRC)

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- \* Started early 1997 by Nox. Quickly became for people on autistic spectrum only after NT visitors wanting to use us as resources.
- \* In text, but still direct/live communication.
- \* Caused many 'real life' friendships and relationships.
- \* Still going strong! <http://asperger.inlv.org/>



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# “(En)countering the Culture of the Norm”

Seminar focusing on culture of autism, Amsterdam, 1999

# alt.support.autism (Usenet)

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- \* Usenet: the largest online public bulletin board system
- \* alt.support.autism created in 1998
- \* Unmoderated, threaded discussions
- \* Participation largely under pseudonym
- \* Remained autistic-dominated somehow

## The alt.support.autism FAQ

*"Organising a group of autistics is rather like herding cats."*

### a.s.a. FAQ

[Home](#)  
[Getting Along](#)  
[Definitions](#)  
[Treatments](#)  
[Issues](#)  
[Insiders](#)  
[Glossary](#)  
[Resources](#)

### Updates and Additions

*Last updated July 18th 2003*

- FAQ now moved to new location at [www.mugsy.org/asa\\_faq](http://www.mugsy.org/asa_faq)
- Contacts for FAQ now Mike Stanton and John Muggleton
- Experimental change to font colours - please provide feedback

alt.support.autism charter (established at the creation of this group in January 1998):

*This newsgroup is for support, information and discussion pertaining to the full spectrum of Autism and related conditions. Participants welcomed include first and foremost people with Autism spectrum conditions (including Autism, Asperger Syndrome, PDD-NOS), but also their parents, professionals working in the field, and other interested people.*

*This is an unmoderated newsgroup. A safe and supportive atmosphere is important and participants are encouraged to govern themselves in this matter. Postings containing binary (= non-text) files, advertising not related to the subject, and other off-topic traffic are inappropriate. Crossposting to other groups is discouraged.*

This Frequently Asked Questions (FAQ) document is produced in response to requests from people who felt that such a guide would help people get more out of the newsgroup from the time they join it. It is not some kind of charter or rule book, and "violations" of the FAQ will not result in anyone being ostracised or condemned. However, it is hoped that misunderstandings will be minimised.

alt.support.autism FAQ (Anna Hayward & Kalen, 2000)

[http://www.mugsy.org/asa\\_faq/](http://www.mugsy.org/asa_faq/)

# Autscape

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- \* Grew out of online autistic space: we want an Autreat-like conference in Europe.
- \* Someone on InLv said ‘Enough talk, who can start a mailing list’? Kalen did, in 2004, and the rest is history.
- \* Autcape 2005 theme ‘Creating Autistic Space’

# Conclusion

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- \* We now have three competing, yet overlapping narratives: professionals, parents and autistics
- \* While the autistic self-advocacy movement is stronger than it was, some other disability advocacy movements are a lot stronger and even dominant
- \* How do we achieve this for the autistic community?

# References / Further reading

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- \* Sinclair, Jim (1994): *Re: Autobiographies*, St John's AUTISM list. (First online use of term 'self-narrating zoo exhibit')
- \* Sinclair, Jim (2010): *Cultural Commentary: Being Autistic Together*. Disability Studies Quarterly, Vol 30, No 1.
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