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## The Strange Case of Amanda Baggs

creative uses of Media in autistic population

While acknowledging the many contributions of Niklas Luhmann in theories of communication, cognition, social systems, mass media, and his study of self-referential closed systems, codifying perception of art, in history and evolution, I can't help but think of Lance Strate and his definitions of autism:

"Even when verbal skills are well developed and intelligence high, autistics have difficulty picking up the meta-communicational and relational cues that typical individuals take for granted." (Strate, *Echoes and Reflections*, p. 121)

Every time I read Luhmann I come up with a new interpretation, a new layer of meaning heretofore missing. Using McLuhan's model of perception, the medium here is overpowering the message, creating obfuscation as a highly developed literary art form in itself. To translate the translation, mass media "are responsible for the production of modern society's '*EIGENVALUES*' - those relatively stable orientations in the cognitive, the normative and the evaluative domain which . . . arise out of operations being applied recursively to their own results." (Luhmann, *The Reality of the Mass Media*, p.99). It is possible then, that even with the fundamental changes in media production by independent, non-affiliated 'autopoetic' journalists, photographers (and YouTube video makers), amateur and professional artists, social critics, and including the social media, Web 2.0, etc; the "reproductive capacity" to "improve and simultaneously normalize a means of communication" (Luhmann, 98) has a robust function in today's world.

What a far cry from the oral culture to the literate, and back again (Ong's second orality – the electronic media). From the 'here and now' to the abstracted, to the 'self-mediated'. (And also from the '*self-mediated*' to the '*self-medicated*'.) Although it has been taught in colleges since the 1970's (Postman, et al) the concept of media ecology as a mental health issue has barely entered the mainstream thought at this particular time of saturated media envelopment and participation. How connected can we be or must we be in order to survive in the Darwinian sense. And how very ironic (or is it an example of McLuhan's law of reversal) that a media specialist (Strate) can have an autistic child whose overstimulation by media can lead to fits of rage, or total shut down of all communicative faculties. Is this representative of society's overloaded plate? Can we draw a parallel between the "epidemic" of autism spectrum disorders and what is transforming society as a whole? And are there serious issues of mental health we need to address in the re-balancing of 'sense ratios'. Strate refers to psychologist Kenneth Gergen (*The Saturated Self*, 1991) that with the impact of

interpersonal media (and this even before the internet had it's baby teeth), "electronic technologies have led to a sharp rise in the number of interpersonal contacts we make and keep up with, and the frequency of our interactions, the number of roles and selves we maintain . . . this results in **the postmodern breakdown of the self** or decentering of the subject."(Strate, 62-63).

On the other hand what a blessed gift to the struggling autistic spectrum of people, from 1 in 1000 just a decade ago to 1 in 100 today (some estimates as high as 1 in 70 for males), that truly interactive media now exist, cool in the McLuhan sense "that maximizes participation because it frees two sets of inhibiting factors" (Levinson, *Digital McLuhan*, p.116). That is, the impossibility of physical meeting and the liberation of time-based communication means that asynchronous call and response are the most successful modes. The actual production of new media - blogs, online diaries, chat rooms, posting of poetry, artwork, (and rants), contains the actual voices of never-before-heard real people. Of course, yes, the doctors and researchers who are studying them are publishing as well, and these papers are available to all who can access the internet; but how valuable and important that this population can now speak **IN THEIR OWN WORDS**, and **IN THEIR OWN CHOICE OF LANGUAGE**. A decade or two ago this wasn't possible. And we are talking about those who don't have a voice other than typing or pasting into a computer and posting it to the world. Or at the very least to their peers.

One inside look at a sensitive poet, photographer and artist is this interesting internal dialogue, which should shed much light on the process and the struggle - these things which we as NT's (*Neuro-Typical*) have not a clue:

"Dear Silence,  
I know you hear me, even though you absorb everything I say without returning an echo.  
These things I yell from between my cupped hands meander about as if avoiding their task.  
It is as if they are afraid of your presence.  
And today you caught me standing around after I'd finished what I said.  
I know you know which words I mean. I'm waiting for your absence, Silence.  
Sincerely,  
Fortitude"

-Poem by Shanti Perez: 1989, posted on <http://shantiperez.blogspot.com>

For Lyn Redwood of FAIR Autism Media ([http://www.youtube.com/watch?v=XB\\_1ohubNMI](http://www.youtube.com/watch?v=XB_1ohubNMI)), her son's first words at 5 years old were "STUPID" to the teacher who turned off his computer, which he was completely absorbed in. Einstein was said to have been mute until quite late in childhood, and this is one of the standard means of detecting Autism:

"Onset must be prior to age three years, with delays or abnormal functioning in either social interaction, language as used in social

communication, or symbolic or imaginative play." -- DSM-IV (Diagnostic and Statistical Manual of Mental Disorders. American Psychiatric Assn 1994).

In a note on his amazing video montage of what it's like inside an autistic mental sky (<http://www.youtube.com/user/aspie182>), Dean McIntosh writes critically of the advocacy organization Autism Speaks: "not a single autistic individual was involved in the process of making decisions". In her book "Through the eyes of Aliens", Jasmine Lee O'Neill a mute autistic savant, (and poet, writer, illustrator and musician) writes

" My goal is to show that autism can be seen as a truly beautiful event. It is quite tiring to read book after book denouncing Autism as a horrible condition. I am qualified to offer an opposite opinion. . . Autistic people are often victims of oppression. They are often discriminated against . . . Autistics can be coached so that they will be able to use the special gifts they have."

According to Simon Baron-Cohen, an important researcher in Autism:

"Children with autism, when studied under experimental conditions, have been shown to have difficulties both in production of deception, but also in understanding when someone else is deceiving them".

(Baron-Cohen, 2001)

Aside from such famous film portrayals like Dustin Hoffman as an autistic savant in *Rain Man* and Robert deNiro as a catatonic in *Awakenings*, there are some emerging media stars or anomalies in this area: notably Temple Grandin. Neurologist and popular author Dr. Oliver Sacks wrote in his 1995 book *An Anthropologist on Mars* about this extremely high functioning autistic PhD professor, animal handler, author and public speaker. Now a movie of her life has been made (Temple Grandin, HBO, Feb 2010). She speaks volumes about her learning difficulties, attempts to decode emotional expressions of others, and her theory of the autistic mind as *Thinking in Pictures*, (also the name of one her books) or thinking in patterns as with music and mathematics (Temple Grandin, *The Way I See It: A Personal Look at Autism and Asperger's*). Her fascinating TED talk included this slide:

**Language covers up the visual thinking we share with animals**



"Cattle are disturbed by the same sorts of sounds as autistic people - high pitched sounds, air hissing, or sudden loud noises; they cannot adapt to these . . . They are disturbed by high visual contrasts, shadows or sudden movements. A light touch will make them pull away, a firm touch calms them."

--Temple Grandin as told to Oliver Sacks in 'Anthropologist on Mars'

*The following story brings up some very interesting points in regard to **remediation** - in all of it's meanings.*

Both CNN and CBC (Canadian) have produced documentary films on Amanda Baggs. She herself has produced 3 videos (which are somewhat spooky, almost sci-fi) accessible on the internet in which she has the computer read her very articulate typed accounts of language processing, cognition, and what it's like to be autistic (<http://www.youtube.com/watch?v=qn70gPukdtY>). Presumably she can't speak. She is featured 'stimming' or self stimulating in repetitive patterns and has created a soundtrack which includes her singing and 'playing' her room. (<http://www.youtube.com/watch?v=JnylM1hI2jc>). She writes on her blog:

"If my senses are overwhelmed I shut down. People may think I'm listening, but I cannot. . . so I tend to shy away from such situations in an attempt to shield myself from the frightening situations that come along with the territory."

"Linguists have written about language vs. intelligence, revealing that one has little or nothing to do with the other. Slurred speech and stuttering have often left people outcast from their peers, deemed incompetent".

"There are different modes of communication. Most people are stuck on words, but the bulk of communication [in social situations] is contained in body language, which is what people with autism have the most trouble understanding. This is because body language is interpreted subconsciously, like a tape running in the background, and people don't even realize they are decoding it as they communicate."

In dialogues among the autistic community blogosphere, she is generally regarded as a fake. The major networks have taken down the links to her documentary. Her own site is a "non-site"(<http://amanda.autistics.org/>) . One person wrote , anonymously:

Yes, there IS a disorder that makes people like Baggs think she is autistic or feign autism. There are two scenarios: either one, she's deliberately faking the autism after studying autistic individuals and reading about how to act autistic, which equals: Factitious disorder. Or, two, she's suffering from psychogenic autism which would be rooted in her Dissassociative Personality Disorder. It's amazing how people these days don't even question anything. The public just believes whatever is presented to them without question...

Another blog, this one from *asberger diary*:

## "If I can't see you, then you can't see me"

(<http://www.psychologytoday.com/blog/aspergers-diary>)

This relates heavily to Strates "Mindblindness" (Strate 121-123).

"Difficulty in understanding other minds is a core cognitive feature of autism spectrum conditions" (Baron-Cohen, 2001).

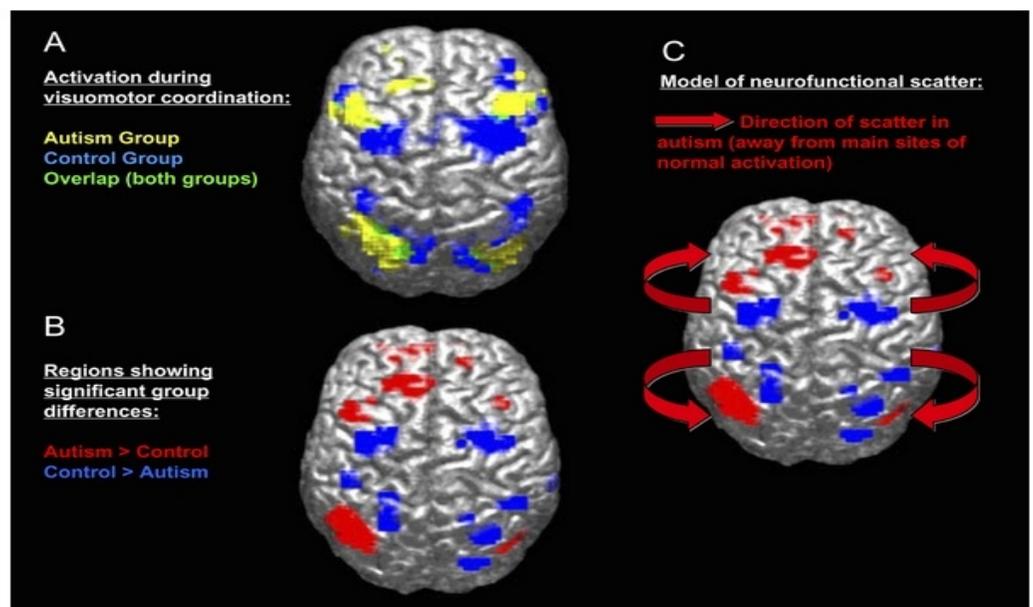
But Baron-Cohen has also discovered a small but statistically significant link between autism and engineering:

" The very same genes that lead an individual to have a child with autism can lead to superior functioning in the domain of folk physics. Engineering and related skills have transformed the way in which our species live, without question for the better. Indeed, without such skills, homo sapiens would still be pre-industrial. " (Baron-Cohen, 1997)

We are discovering great potential and new insights using tools of creative, autobiographical media. Probing the possible modes of language other than the obvious are a door into the minds of mysterious pathologies, misunderstood people, and societal behavior. The root causes of autism appear to be neurological, genetic, and probably environmental - the increase of heavy metals such as mercury and the body's inability to process or metabolize them ([http://www.autism-society.org/site/PageServer?pagename=research\\_envirohealth](http://www.autism-society.org/site/PageServer?pagename=research_envirohealth)). Alexander Durig writes of Bernard Rimland's "inquiry into the biochemical underpinnings of autistic perception . . .how allergens and toxins can affect the brain and central nervous system" (A.Durig, How to Understand Autism, 2005).

While these issues are being addressed, it is the structural theory of mind, perceptual and behavioral models, and the brain itself that are being mapped.

(Kendall Powell, *Opening a Window to the Autistic Brain*)



**Figure 1.** Brain Activation Scattering in Autism

Autistic individuals show less activity, during a movement task, in areas that are normally activated (premotor and superior parietal cortex; blue areas), but unusually increased activity around these normal sites of activation (red areas). Images courtesy of Ralph-Axel Müller.

My own interest in the subject is a result of being a teaching artist in the New York City school system and beyond. For the last few years I've been developing innovative curriculum in regular and special needs populations (formerly known as District 75), mostly in elementary schools. I have participated in and witnessed the amazing breakthroughs of music and art as transformative experiences. Sometimes the only way a child can communicate is through the expressive and creative modes of art. These languages of media are one of the main ways to counter anti-social and non-social behavior, simultaneously encouraging a learning environment of multiple intelligences. As a matter of fact, music and especially rhythm are the immediate indicators of an individual's relationship to a group - you can hear when you're out of tune or out of tempo. In terms of violence prevention, 'tis far better to hit a drum than to hit your neighbor. And since synchronicity is a powerful indicator - have a happy **World Autism Day** April 2<sup>nd</sup>, celebrated in countries across the globe.

### WORKS CITED

Strate, Lance , *Echoes and Reflections*, Hampton Press, NJ; 2006

Luhmann, Niklas, *The Reality of the Mass Media*, Stanford University Press, California, 2000 [translated from 1996 edition Westdeutscher Verlag]

Gergen, Kenneth, *The Saturated Self*, Basic Books, NY; 1991

Levinson, Paul, *Digital McLuhan*, Routledge, London & NY; 1999

O'Neill, Jasmine Lee, *Through the eyes of Aliens*, Jessica Kingsley Publishers; 1999

Simon Baron-Cohen, *Theory of mind in normal development and autism*,  
Departments of Experimental Psychology and Psychiatry, University of Cambridge; 2001

Simon Baron-Cohen, Sally Wheelwright, Carol Stott, Patrick Bolton, and Ian Goodyer,  
*Is there a link between engineering and autism?*  
Departments of Experimental Psychology and Psychiatry, University of Cambridge  
Downing St, Cambridge, CB2 3EB, UK. ; 1997

Oliver Sacks, *An Anthropologist on Mars*, Alfred A. Knopf, NY; 1995

Grandin, Temple, *The Way I See It: A Personal Look at Autism and Asperger's*, Future Horizons, Arlington, TX; 2010

various authors: *Telling the Story: Autism in the Media*, Psychology Today website

Durig, Alexander, *How to Understand Autism*, Jessica Kingsley Publishers; 2005

Powell, Kendall, *Opening a Window to the Autistic Brain*, PLoS (Public Library of Science) Biol 2(8): e267; 2004