Metaphors of Autism, and Autism as Metaphor: An Exploration of Representation

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Psychoanalysis teaches us that all myths...have their source in an unconscious wish. Often the same myths are called on to relieve deep anxieties by suggesting that once we lived without fear or despair and may do so again. Sometimes the myth contains a kernel of truth...behind the elaborate tales spun around them...

Starting a 21st century paper on autism with a quote from Bruno Bettelheim feels like a heretical act. After all, Bettelheim's theories about this neurological condition have long since been discredited, along with the veracity of his case studies and accounts.² But as this work concerns itself with the metaphors of autism, returning to a writer whose metaphors exerted particular power for decades seems strangely appropriate.

Bettelheim's metaphors, and those that succeeded them, have become myths embedded within the narratives of autism. These mythic narratives constrained the representation of people with autism, and were unchallenged until the relatively recent production of counter-representations by people with autism themselves.

In this paper, I attempt to interrogate some of the most commonly used metaphors of autism, examining their function as metaphors and the meanings they may carry. I also attempt to contrast these metaphors with metaphorical constructions utilised by people with autism. Finally, I examine the use of autism itself as a metaphor.

Interrogating the empty fortress

The use of metaphor in "scientific" discourse has often been questioned, not least by Foucault, who said: "The similar, which was for a long time a fundamental category of knowledge—at once form and content of cognition—found itself dissociated in an analysis based on terms of identity and difference... Similarity is no longer the form of knowledge, but instead the occasion of error, the danger to which one exposes oneself when one does not examine the poorly-illuminated place of confusions." This analysis places metaphor in the same category as rhetorical techniques, as a linguistic artform that can be used to paper over cracks in theory, or to discourage direct investigation by substituting poetic comparison. Sontag also criticised the use of metaphors, even "empowering" metaphors, in the disease narrative.⁴

This is not to say that one can construct a metaphor-free discourse of medicine or disability, or even that such a discourse would be desirable. But as Bernhard Debatin notes, the search for knowledge and meaning requires that metaphors be assessed from a variety of angles, even as we re-examine the objects they have been used to describe.⁵

Bettelheim's use of emotionally stirring language and potent metaphors built a dramatic narrative of autism whose moment on the stage was prolonged by its aesthetic, even romantic, appeal. He titled his seminal work on autism *The Empty Fortress*: an image that carried within it most of the metaphors of autism since employed. These include the essential emptiness, otherness, or non-humanness of people with autism; the idea of a "real" self that is hiding, missing, estranged, or asleep in people with autism; military metaphors; and the concept of autism, or the person with autism, as an enigma or puzzle.

Mikko Lehtonin defines the metaphor as "a linguistic image which produces meanings through analogies, by explaining or interpreting one thing through another." He adds that while metaphors are often employed as a sort of verbal shorthand, as in the case of calling the corner support of a table a "leg," they can also serve as containers for added meaning, not just helpful analogies.⁶

As an assiduous student (and spinner) of myths, Bettelheim was well aware of that second usage. His metaphorical choice was unlikely to be a mere flight of fancy. In a Germanic myth that became part of both Arthurian legend and Wagnerian opera, the holy fool turned knight Parsifal enters an "empty fortress," the castle Monsalvat, in search of the Holy Grail. Knowing of Bettelheim's interest in mythology, it's tempting to think that this legend somehow emerged in his mind as he searched for that perfect metaphor of autism as he saw it.

There are certainly several interesting correlations. First, there is the similarity between the character of Parsifal and the autistic child as conceived by Bettelheim. Parsifal is a naïve and odd boy, as his mother has kept him isolated to protect him from the temptation to perform deeds of heroism, a passion that claimed his father's life. When he does go out into the greater world, he commits a number of egregious acts due to his naïveté, and is saved from harm only because his inner nature is pure. It is that guiltless inner nature that makes him the only knight of the round table worthy of finding the Holy Grail.⁷

If breaching the walls of the empty fortress to liberate the Holy Grail was Parsifal's quest, Bettelheim's use of the metaphor positions the therapist's quest as breaching the defenses of the autistic child to reveal his human self. By doing so, he declared that the "problem" of autism lay within the child,

who Bettelheim believed had built these barriers as a defense against abusive parenting. The "problem" was insoluble unless the child, like Parsifal, gained enough insight into his condition to overcome his self-built walls, and unless the intervening obstacles to enlightenment (in this case, parental malfeasance) could be removed. This could only be done through the guidance of a specially trained therapist who would guide the child on his quest.

In *The Empty Fortress*, Bettelheim urges would-be rescuers to prepare the child as if to undertake a perilous quest: "Just because it is the most important progress the autistic child can make, the time, place, and conditions for a symbolic re-experience of earliest infancy, if not of life in the womb, must be his own spontaneous choice...Thus we cannot tempt or induce the child to take such a course. All we can do is create the most favourable conditions for so extreme an emotional venture."

Coupled with the metaphor of the imprisoned, hidden, invisible, or sleeping child, the rescuer motif buttresses a particularly pervasive myth: that inside the child with autism there is a "normal" child struggling to get out, awaiting a hero who can unlock his or her prison.

Who is the real hero?

Although one reading of the empty fortress metaphor positions the person with autism as, potentially, the hero of his or her own story, it paradoxically gives the therapist/helper an even greater status, as the enlightenment quest can only occur with the assistance of an appropriate catalyst. Of course, this concept has a strong attraction for people who want to help affected children, whether out of altruism or for self-gratification.

The equation of therapist/helper and hero is vividly painted in the many articles and books written by, about, or for "heroic" teachers, therapists, and parents: for example, therapist Virginia Axline tells us she was dubbed "the lady of the wonderful playroom" by her grateful patient, "Dibs." A biography of Francis Tustin makes it clear that she saw providing therapy to autistic children as a religiously inspired mission. ¹⁰

So while on one hand an idea is put forward, through the metaphors of the empty fortress and the sleeping or hidden child, that the "problem" of autism is within the affected child, the concept of the hero-therapist riding to the rescue places its solution elsewhere.

The heroic ideal is sometimes expressed in more mechanistic terms, using the metaphor of the lock and key. The "key" might be a person or a method, but regardless of the metaphor employed, the message is that some special outside influence is required to unlock the potential of the person with autism. This metaphor is redolent of changeling myths, which may represent the oldest legends concerning autism as such. In these stories, the changeling must be killed, beaten, or abandoned, or the correct spell must be said, to force the return of the "real" child it replaced. ¹¹

Accordingly, representing the care, education, and treatment of autistic people as heroism may have pernicious effects. Not only does it position people with autism as abnormal and so in need of normalising actions, it also tends to encourage the use of "heroic measures" in the quest for a cure. Perhaps as a result, people with autism have been subjected to a variety of unpleasant and even dangerous programmes, ranging from untested drugs and therapies to restraints and "rebirthing." ¹²

Human nature and animal nature

Metaphors of ferality, wildness, or animalisation are also common within narratives of autism. Rarely are these metaphors interrogated, but they have the obvious effect of rendering their subjects as less than human. Bettelheim described children with autism as being "dehumanised." Frances Tustin even described them as "monsters."

Dehumanising metaphors can have very real effects on care and treatment decisions. For example, although the use of overt behaviour modification techniques on humans became somewhat taboo following World War II, even theorists who attacked the work of B.F. Skinner seemed to not be bothered about the continuing use of such methods on animals and "subnormal" children, in particular children with autism. Indeed, years after laws have been passed discouraging the use of aversive conditioning in animal training, such practices are still used in the treatment and education of children with autism. Only recently have the implications of this been publicised. As one organisation opposing these practices has written: "The use of aversives is a human rights issue and a civil rights issue. When we allow punishments to be used on persons with disabilities which would be illegal if used on persons without disabilities, we are denying them equal protection under the law. Even our other devalued populations—people who are elderly, homeless, or in prison—cannot legally be 'treated' with aversives, nor do we permit animals to be trained or treated by these means."15

In another example, the "wild child" known as Genie, who was not autistic but displayed similar impairments as the result of severe childhood deprivation, was celebrated as a modern-day Kaspar Hauser, giving researchers a chance to study abnormal development at close range without conducting the "forbidden experiment" themselves. It's less well known that when the funding grants ran out, Genie was abandoned to live first with the

mother accused of neglecting her, and later in a series of institutions. She was, quite literally, "treated like an animal" whose usefulness as a lab specimen had expired. 16

A more ominous connection can be made with the sadly frequent "mercy killings" of people with autism by their caregivers. Such crimes are almost never punished, because we find it easy to devalue the victims while pitying the carers. ¹⁷

Occasionally people with autism themselves express an affinity with animal metaphors. Temple Grandin, an adult with autism who is an animal behaviour expert, has said: "My life as a person with autism is like being another species: part human, part animal. Autistic emotion may be more like an animal's." However, one could say that Grandin's words expose the way that humanity itself is socially constructed. This epistemological analysis has been put forward in regards to learning difficulties, a categorisation that intersects with that of autism. ¹⁹

Military metaphors

Military metaphors are frequently used in texts about autism, from Clara Claiborne Park's personal account of parenting a child with autism, *The Siege*, to the name chosen by a current medical research group, Defeat Autism Now!

It can be argued that these metaphors lead inexorably towards heroic treatment decisions: if the person with autism is within a fortress, must not that fortress must be confronted, attacked, besieged, conquered? Such metaphors appear frequently in texts inviting readers to break the barriers of autism, or to confront, attack, and overcome the condition.

These metaphors seem to position autism as something outside the person diagnosed with it (although as Jim Sinclair notes, this is not how this discursive practice is perceived by people with autism²⁰), and represents it as something negative and unwanted.

Puzzling metaphors

The medicalisation of autism has led to a new set of metaphors. Perhaps the most common is that of the puzzle. Uta Frith may have pioneered this metaphor with her primer on the condition, *Autism: Explaining the Enigma.*²¹ Major autism support and research organisations, including the National Autistic Society in the UK and the Autism Society of America, use a puzzle piece as part of their logos. As every condition must have a corresponding awareness ribbon these days, one sees a ribbon printed with a multicoloured jigsaw puzzle motif, and often centrally anchored by a puzzle piece, on the

lapels of many people who wish to make public their concern for or connection with people with autism.

But there are a number of problems with the puzzle metaphor. As with its predecessors, it locates the "problem" within the affected person, but places the solution outside that person. It reinforces the idea of the person with autism as an object to be acted upon: a puzzle to be solved. The puzzle metaphor advertises for a new kind of hero—this time, a puzzle-solver employing research, methodologies, and medications—to put the pieces back together.

It encourages a view of autism as a mystery, unique and without relationship to other neurological conditions, and as something to be solved or put back together by experts. Amanda Baggs, who has an autism diagnosis, wrote the following in a satirical text entitled "How To Become an Autism Expert": "Mysterious [and] similar words, such as strange, puzzling, bizarre, and so on ... adds an air of mystery to autism. It makes autism seem like something exotic. If you are making a logo, incorporate puzzle symbols into it for a similar effect."²²

More importantly for people with autism, the puzzle metaphor questions their integrity as human beings. It says they are missing something, and that they need to be fixed. One person with autism, Laura Tisoncik, has responded to the puzzle metaphor by designing and distributing a button that reads "I am not a puzzle/I am a person."²³

Countering representations

In *Bad-Mouthing: The Language of Special Needs*, Jenny Corbett notes that the discourse of psychology relies heavily on metaphor, and is largely responsible for bringing literary conventions and "poetic imagery" into common use in discourse about disability. She says: "In the use of such metaphors, [the author] indicates how hazardous a process of definition this procedure was and how easily it could be prone to error."²⁴ Corbett goes on to explore the undertone of some metaphors—for example, the equation of "normal" intelligence with light, and "subnormal" intelligence with evergreater degrees of darkness, with all the cultural baggage that entails—and follows with an indictment of the use of poetic language and metaphor to obscure processes of objectification, abjection, and control.

Jim Sinclair, a person with autism, has directly addressed the troubling effect of these dominant representations of autism:

Autism isn't something that a person has, or a "shell" that the person is trapped inside...Autism is a way of being. It is not possible to separate the person from the autism.

Therefore when parents say,
I wish my child did not have autism,
What they're really saying is,

I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.

This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.²⁵

Sinclair and many others have presented their own experiences through articles, books, Web sites, and speeches. Although people with autism do sometimes use metaphor to explain their experiences to non-autistic people, the metaphors they choose and the lived experiences they relate challenge both the current medical model of autism and the ways in which people with autism are usually represented.

The metaphors employed by people with autism position themselves as normal but different. Metaphors of people with autism as strangers, or even as aliens, have frequently been highlighted. These place the "problem" and its solution outside the person with autism, in accordance with the social model of disability: the "problem," they proclaim, is not autism or people with autism, but the rigid social structures and expectations of mainstream culture. They position autism as a culture, not a problem, in much the same way deaf culture has been constructed. They reculturise autism, exposing the epistemological impacts of dominant representations.

These counter-representations also encourage examination of larger assumptions about normality, impairment, and difference. Jonathan McNabb writes: "Personally I find the basic stumbling block... is the assumption most Neurotypical people have that [the] Neurotypical worldview is neutral and normative... Autism is then seen in contrast to this given, natural, neutral and normal society."²⁷

Autism as metaphor

McNabb pinpoints the fact that representations of autism have frequently been deployed to define the borders of normalcy. Indeed, autism is diagnosed via purely subjective criteria: to be so labeled, a person must be judged to function abnormally in a series of ways. ²⁸ Defining the norm by delineating its margins is a process familiar to most researchers, as it is so frequently employed in the social norming associated with gender roles and sexuality in

particular.

However, some have gone beyond this relatively typical exercise in norming by comparison, extending their usage of autism into a wider, and not strictly metaphorical, construct. "Pop psychology" theorists like R.D. Laing, Erich Fromm and Joseph Chilton Pearce have been particularly fond of using autism as an exemplar, building on the groundwork laid by their more academic colleagues. For example, therapist Margaret Mahler represented people with autism as non-human, describing them as exemplifying "a loss of that primordial differentation between living and lifeless matter." Fromm and others used this representation to construct autism as a metaphor for the rise of an inhuman, materialistic modern culture. But while one might assume that these theorists intended only a metaphorical construction, using the concept of autism as a form of descriptive shorthand for how an alienating culture may cause people to display obsessive-compulsive behaviours or find relationship formation difficult, Fromm and Pearce (among many others) went further, claiming that an alienating culture actually causes the condition autism. ²⁷

When people with autism talk about an "autistic culture," the phrase carries quite different meanings. For activists like Martijn Dekker, autistic culture represents self-advocacy, the creation of counter-representations by people with autism, and insistence on self-determination.³⁰

This use of autism as metaphor reflects back the way metaphors of self-loss, otherness, and animalisation/dehumanisation have been used to describe autism itself. These metaphors say little about autism as a condition, while speaking volumes about cultural anxiety and the use of representations of disability in the discourse of humanness. As the echoes of the Parsifal legend within the empty fortress metaphor of autism indicate, the representation of people with autism has been entwined from the beginning within an effort to define what it is to be normatively human, a definition traditionally based on myths of purity rather than complex and sometimes troubling realities.

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Notes

- 1. Bruno Bettelheim, *The Empty Fortress: Infantile Autism and the Birth of the Self* (New York: The Free Press, 1967), 13.
- 2. Pollack, Richard, *The Creation of Dr. B: A Biography of Bruno Bettelheim* (New York: Simon and Schuster, 1997).
- 3. Michel Foucault, *Les Mots et les Choses* (Paris: Gallimard, 1966), 65-68., quoted in Bernhard Debatin, ""Metaphorical Iconoclasm and the Reflective Power of Metaphor," in *Metaphor and Rational Discourse*, ed. Bernhard Debatin, Timothy R. Jackson and Daniel Steur (Tübingen: Niemeyer, 1997), 147-158.
- 4. Susan Sontag, *Illness as Metaphor and AIDS and its Metaphors* (New York: Picador USA, 2001).
- 5. Bernhard Debatin, "Metaphorical Iconoclasm and the Reflective Power of Metaphor," in *Metaphor and Rational Discourse*, ed. Bernhard Debatin, Timothy R. Jackson and Daniel Steur (Tübingen: Niemeyer, 1997), 147-158
- 6. Mikko Lehtonin, *The Cultural Analysis of Texts* (London: Sage Publications, 2000), 25-27.
- 7. Wolfram von Eschenbach, *Parzival* (New York,: Penguin USA, 1980).
 - 8. Bettelheim, 294-295.
- 9. Virginia Axline, *Dibs In Search of Self* (New York, Ballantine Books, 1964), 204.
 - 10. Sheila Spenseley, *Frances Tustin* (London: Routledge, 1995).
- 11. D.L Ahliman, "Changelings," *Folklore and Mythology Electronic Texts*, 3 September 1997 (20 June 2003). http://www.pitt.edu/~dash/changeling.html>.
- 12. The use of untested, potentially dangerous, and occasionally deadly "treatments" for autism is well-documented. These have variously included full or partial physical restraint; operant conditioning using aversives, such as mild electric shocks or physical blows; and a wide variety of drugs, ranging from LSD to powerful tranquillisers. As of this writing, no form of medical, educational, or therapeutic treatment has been proven effective for all persons with autism.
 - 13. Bettelheim, 7.
- 14. Francis Tustin, *Autistic States in Children* (London: Routledge, 1992), 13.

- 15. Autism National Committee, "Myths and Facts About Aversives," *Autism National Committee*, 6 January 1999, (20 June 2003). http://www.autcom.org/myths.html>.
- 16. Russ Rymer, *Genie: An Abused Child's Flight From Silence* (New York: HarperCollins, 1993), 149-194.
- 17. CBC News Online staff, "Quebec Mother Charged with Killing Disabled Daughter," Canadian Broadcasting Corp. Online, 21 March 2001, (20 June 2003). http://cbc.ca/cgibin/templates/view.cgi?/news/2001/03/20/rett010320; Jenifer B. McKim, "Autism a Stress Overdose: O.C. Man's Shooting of Afflicted Son Was Extreme, But All These Families Can Relate to the Pressure Involved," Orange County Register, 3 August 2002, sec. A, p. 6.
- 18. Temple Grandin, "Thinking Like Animals," in *Intimate Nature: The Bond Between Women and Animals*, ed. Brenda Peterson, Deena Metzger and Linda Hogan (New York: Ballantine Books, 1998), 176-179.
- 19. Dan Goodley, "'Learning Difficulties,' the Social Model of Disability and Impairment: Challenging Epistemologies," *Disability & Society* 16, No. 2 (2001), p. 207-231.
- 20. Jim Sinclair, "Don't Mourn for Us," *Our Voice* 1, No. 3 (1993). http://web.syr.edu/~jisincla/dontmourn.htm>.
- 21. Uta Frith, *Autism: Explaining the Enigma* (Oxford: Basil Blackwell, 1989.)
- 22. Amanda Baggs, "How To Become An Autism Expert (V1.2)," *Autism Information Library*, 2002, (20 June 2003). http://www.autistics.org/library/autexpert.html>.
- 23. Laura Tisoncik, "Buttons," *autistics.org: Resources By and For Persons on the Autistic Spectrum*, 30 May 2003, (20 June 2003). http://www.autistics.org>.
 - 24. (Corbett 1996, 19)
 - 25. Sinclair, op. cit.
- 26. Jasmine Lee O'Neill, *Through the Eyes of Aliens: A Book About Autistic People* (London: Jessica Kingsley, 1998); J. Blackburn et al., "A Discussion About Theory of Mind: From an Autistic Perspective," paper presented at Autism Europe's 6th International Congress, Glasgow, Scotland, May 19-21 2000; Jane Meyerding, "Thoughts on Finding Myself Differently Brained," *Independent Living on the Autistic Spectrum*, 1998 (20 June 2003). http://www.inlv.demon.nl/subm-brain.jane.eng.html; Robert S.P. Jones et al., "First-hand Accounts of Emotional Experiences in Autism: A Qualitative Analysis," *Disability & Society* 16, No. 3 (2001): 393-401.

27. Jonathan McNabb, "I Don't Want to Be a Pioneer I Just Want to Be Me," *Autism Information Library*, 2001, (20 June 2003). http://www.autistics.org/library/nopioneer.html>.

- 28. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders IV-TR* (Washington, DC: American Psychiatric Association, 2000).
- 29. Margaret Mahler, On Human Symbiosis and the Vicissitudes of Individuation, Vol. 1 (New York: International Universities Press, 1968.)
- 30. Joseph Chilton Pearce, *Magical Child: Rediscovering Nature's Plan for Our Children* (New York: E.P Dutton, 1977), 16-17; Erich Fromm, *The Anatomy of Human Destructiveness* (Greenwich, Conn.: Fawcett, 1973), 389-398.
- 31. Martijn Dekker, "On Our Own Terms: Emerging Autistic Culture," *Beyond Autism*, 1999 (20 June 2003). http://trainland.tripod.com/martijn.htm.

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