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<http://socialalternatives.com/issues/visibility-making-disability-visible-through-artistic-discourses>

Inspiration is Power: Voices of information and advocacy for the reader of autism narratives

MICHAEL WHELAN

The central idea that the article engages with is that there are at least two fundamentally differing rhetorical positions on autism. The first position is that of the authoritative biomedical voice which identifies and pathologises a collection of behaviours, labels it as 'located within the autism spectrum' and then seeks either to measure its degree of severity or to medicate it. The second position is that of the parent of the autistic child who characterises the disorder as a demonised invader of their child, thief of their future and which through acts of heroic intervention can be exorcised. The most potent difference for the lay reader in engaging with these two discourses is the degree to which they limit or enable the reader to act or to respond. Inspiration is Power critiques the roles of biomedical and pathographic texts in telling the stories of autism.

In March 1996 my life changed forever with the birth of my first child, Connor. As with all first-time parents, my world view, philosophical assumptions and personal priorities were tossed into the air and on their return to Earth, settled in a range of locations that I would not previously have been able to foresee. My professional life as a university music lecturer initially became a complicated distraction to the wonders of new life and then, almost as quickly a snug refuge from the hourly crying, feeding, nappy changing and general chaos that a new baby brings to orderly suburban homes. I cast myself enthusiastically into the role of new committed father with the purchase of a wide range of products designed to telegraph to the public gaze our allegiance to a carefully chosen set of values. We were educated, outdoor, safety conscious, creative parents with an eye on the environment and a subscription to Choice magazine. Once the dust had settled and a routine was in place, my wife and I immediately planned a second child to partner our first in a life of choreographed adventures, schoolyard discoveries and family bliss. Sixteen months later in July, 1997 our second child Lachlan was born amid a chorus of family joy and triumph and a more sober and informed redistribution of personal priorities and philosophies. Despite the temporary derailment of domestic order and repeated disruption to routine and priorities, we were soon back on the rails with a Disney roadmap of life adventures in place.

However, as Connor approached eighteen months of age, his developmental milestones, which to this point had been boringly consistent with statistical norms, began to regress. His language diminished, he started to lose eye

contact with us and he began to retreat from all contact with his family and his environment, choosing instead, for example, to play repetitively with a single toy for hours at a time. His happy demeanour was replaced now by almost constant crying, restless irritability and self-absorption. His fixation with a single object or ritualistic play routine could see him secluded in his own world for extended periods of time and if interrupted, was capable of intense and lengthy bouts of uncontrolled screaming. The subtly eccentric behaviours that Connor began to exhibit at eighteen months of age intensified over a four month period to the point where at age twenty-two months we decided to have him assessed by our family GP. The doctor assured my wife and me that while there was some evidence of unusual behaviour and delayed development, she believed that a thorough evaluation by a developmental paediatrician would ease our concerns. Our personal narrative of 'obsessive parents with quirky child' was shattered when, two weeks before Connor's second birthday, a paediatrician diagnosed him with severe Autism Spectrum Disorder, a life-long condition for which there is no cure. Our colourful family folklore of eccentric cousins and late bloomers was instantly silenced by this unwavering voice of biomedical authority.

After several weeks of numbing and incapacitating grief, we began in a more systematic and strategic way to try to answer the questions that our family and friends were asking and that we were also asking ourselves. What is autism? Is there a cure? What is the treatment? What do other parents do when their child is diagnosed with autism? What will Connor be like when he is an adult? Will he recover? Will everything ever be normal again?

Thus began our journey of research and therapeutic intervention that continues to this day. Our research over the following months and years emerged from two very different genres of writing, each speaking to a distinctly different audience. The first was the biomedical voice which focuses on the physical processes of illness such as the pathology, biochemistry and the physiology of disease and which speaks to the scientific reader. The second was the parental autobiography; the personal accounts from parents of their journeys parenting a child with autism, providing emotional and practical roadmaps for action and speaking to a much broader general readership.

In the years immediately following Connor's diagnosis, I was passionate and driven to succeed in my search to understand and perhaps even cure my son's autism. While the term 'lay' normally operates within a religious setting, the certainty provided by the search for a cure and hope for my child empowered me with the moral authority, if not spiritual zeal, to boldly engage with this foreign literature. Like most religious orthodoxies, biomedical science operates within a similarly structured hegemonic setting of jealously guarded specialised knowledge (Gwyn 2002; Silverman 1987) whose alternative readings may be strenuously opposed. This literature search was the beginning of what has become a personal quest narrative of hope and recovery. Gwyn (2002) writes of three dominant strategies in medical narrative. The first is the *restitution* narrative in which health is regarded as the normal state to which the 'sick' person will be ultimately restored. The second is the *chaos* narrative where the illness lacks causality, sense and predictable trajectory and subverts the expectation that one event leads to another. The third and final narrative that Gwyn discusses is the *quest* narrative. Loosely based on the Jungian notion of the monomyth, the *quest* narrative follows the arc of a hero who suffers, acquires knowledge and then returns triumphantly to make that knowledge known. In my own rhetorical way, I hitched my wagon to this caravan of wounded storytellers on a rescue mission to slay the dragon of autism.

The American Psychiatric Association's Diagnostic and Statistical Manual (2013) speaks directly to psychiatrists, general practitioners and allied health workers around the world. Unlike most biomedical discourses that deal with diagnosis and pathology, the DSM is notably devoid of a narrative metaphor such as bio-militarism. Bio-militarism grew in popularity based upon Pasteur's concept of the disease as invading agent and Koch's adversarial description of the aggressive bacteria. Military metaphors such as attacking viruses, defences being weak and fighting infection not only proliferate the majority of biomedical narratives, but also pathographic narratives where frequent attacks, battles and victories characterise the dramatic arc of most stories. *Illness*

as *Metaphor* (Sontag 1978) profoundly influenced the characterisation of illness and the mythology of patient as victim in an adversarial relationship. The absence of this common metaphor in the DSM text may be due to the discipline's focus upon behavioural presentation rather than pathological causation.

In addition to the biomedical texts that articulate every aspect of the disorder's symptomatology, pathology and prognosis, I encountered a body of illness narratives chronicling the experience of parenting a child with autism. Books such as *The Siege* and *Exiting Nirvana* (Claiborne-Park 1997, 2002) *Let Me Hear Your Voice* (Maurice 1993) and *Facing Autism* (Hamilton 2000) were benchmark texts in the genre and required reading for any parent of a child newly-diagnosed with autism. *Emergence*, *Labelled Autistic* (Grandin and Scariano 1986) and *Nobody Nowhere* (Williams 2002) delivered fascinating insights into the autistic experience. These books reflect what critics have recognised about illness narrative:

... unlike the biomedical narrative, [it] is reflective, situational, emotional, detailed (often to the point of extreme and saga-like length). Based on the diarist's journal, it takes the form of a memoir and is dedicated to the inscription and celebration of one human life (Wiltshire 1998).

The narratives of these human lives, unlike the socially neutered biomedical hosts, were rich in emotion, inspiration and personal experience and spoke directly to the human experience.

But what is a narrative? An expansive body of scholarship in modern narratology draws upon two primary intellectual schools: the Anglo-American work of James, Lubbock, Forster and Booth with Russian formalist influences of Schlovsky, Eichenbaum, Jakobson and Propp, and the French structuralist approaches of Levi-Strauss, Barthes, Genette and Todorov (Chatman 1981). Chatman goes on to suggest that, 'Narrative itself is a deep structure quite independent of its medium. In other words, narrative is basically a kind of text organization, and that organization, that schema, needs to be actualised: in written words, as in stories ...' And more specifically, what is a pathographic narrative? Hawkins describes pathography as the 'autobiographical or biographical narrative about the experience of illness'. For the purposes of this essay, I refine this category further to specifically discuss the stories of parents writing relational narratives of their children with illness or disability; let's say pedia-pathography.

While the term narrative provides a snug umbrella for the range of pathographic testimonies that tell autism

stories, how does narrative analysis connect with the biomedical text? Does the biomedical voice have a story to tell? Segal (2005) notes that 'Narrative has found a place in health research, not only among the social science and humanities researchers but also among some medical researchers as the default opposite of biomedical discourse'. She goes on to suggest that rhetorical enquiry into the scientific narrative is providing deep insights into the traditions, audience and methods of the biomedical voice. Oliver Sachs's naratological accounts of patient stories in *The Man Who Mistook his Wife For a Hat* (1995) and *Musicalophilia* (2007) deliver potent parallel counterpoints to the biomedical script. Segal (2005) writes, 'opening up social science to literary theory, hermeneutics, and phenomenology, rescuing social science from being strangled by empirical foundationalism'. Rouse (1996) suggests that while the legitimacy of the scientific narrative is grounded in a number of well-established traditions, there is no canonical 'meta-narrative' into which all of its many 'stories' can be resolved unlike the pathographic account of illness which finds its readers browsing through the creative non-fiction shelves of any suburban bookstore.

While Rouse (1996) questions the absence of a unifying narratological schema in the scientific stories, there is no doubting the rigorous traditions of evidence-based scholarship that underpins them. Further analysis into the way in which the scientific voice communicates to its collective readership provides valuable insights into the specific device that can impact upon the lay reader. The DSM's diagnostic criteria are used to set protocols for everything from health plan reimbursement for doctors and hospitals, style guides for academic journals to assisting suburban general practitioners with complex diagnoses (Hacking 1995). The narrative plotting of the DSM can be best described as a linear reductive sequence. Each chapter commences by characterising broad features of the disorder and then progressively addresses more specific issues of associated features, age and gender issues, prevalence and familial patterns and then concludes by proposing a finite set of diagnostic criteria.

The collaborative authorial voice is an anonymous collective of the scientific and intellectual elite gathered under the corporate banner of the American Psychiatric Association. However, the highly objectified scientific style of the voice fails to locate the authorship in any specific cultural or ethnic context. The absolute absence of reference to social or cultural processes or to related scholarship in the field of enquiry suggests an almost biblical omnipotent super-monologue existing on all continents simultaneously. The tactic of making content everything and expression nothing was suggested by Barthes (1996) who went on to say that the scientist as

author must become 'an anonymity, an absence, a blank space'. The DSM has coopted this authorial timbre with an exacting vigour.

The implied audience of the DSM could be collectively characterised as the scientific or clinical reader. The technical language used in the text starkly reinforces the barrier between those who can understand, and those who cannot. Barthes (1996) writes that a professional discourse of this nature 'exalts, reassures all the subjects *inside*, rejects and offends those *outside*' although my response rather than that of offence, was that I found its certainty reassuring but its coldness numbing. The mystification of the ordinary, through jargon and specialised language that is the hallmark of most scientific writing is minimal in the DSM, which articulates with depth and clarity a wide range of social, behavioural and developmental problems. The glaring omission in the text for the lay reader is the absolute lack of empathy and social context for the narrative. The lay reader could be forgiven for assuming the disorder under examination resides in a social and cultural vacuum.

The overall motive of the DSM seems to be to globally standardise the diagnosis and treatment of mental illness through a coherent technical discourse. No doubt the primary motive of such socially and culturally barren writing is to limit the opportunity for misinterpretation for this global professional audience, to negate the difference between a point of view with the point of view. The role of social translation and cultural enrichment is presumably left to the suburban general practitioner or specialist physician to interpret these barren clinical facts and unravel the implications for the patient, their family and the uncertain future that awaits them. The process of dehydrating food for long-term preservation comes to mind, where at the moment prior to packaging, every particle of moisture is removed to maintain the ongoing integrity of the food, only to be reconstituted to its original state with the user adding life-giving water. The role of the medical practitioner could not be more crucial in this process of rehydrating a dry and barren message from its cryogenically frozen state for human consumption. Their ability to contextualise this socio-culturally neutered text for the patient is of utmost importance, but personal experience suggests to me that the re-humanising of this rarefied voice at the coalface of primary care is not a foregone conclusion.

As a lay reader, if I am required to interpret biomedical texts such as the DSM and generate the required socio-cultural contextualisation, then I must do so within the framework of my own experiences. Mailloux (1989) writes that for this 'accomplishment of meaning' to take place, two fundamental positions must be reconciled. The first is that of textual realism where he suggests

that the text exists independent of interpretation where meaning is discovered, not created. The second is the notion of hermeneutic or 'readerly' idealism which argues that interpretation constructs the signifying text and that 'meaning is made, not found'.

Without schooling in the codes and mores of the medical voice, it is possible my quest narrative was doomed to fail without the necessary immersion in this scholarly discipline. Eco (1979) describes the author organising text through a series of codes that assign meaning to the expressions he uses. He writes that 'To make his text communicative, the author has to assume that the ensemble of codes he relies upon is the same as that shared by his possible reader'. My experience of the DSM is that it doesn't contain deeply coded narratives of human experience, cultural impact and social implication. And consequently as a lay reader, I was unable to process the text and access the rich human layers of this invisible apparatus by taking what Eco (1979) describes as 'inferential walks'. Scholes (1981) suggests that these inferential walks are the construction of meaning by the reader filling in the text with their own 'ghost chapters'. With regard to the process of communication, Mailloux (1989) writes that 'a text is frequently interpreted against the background of codes different from those intended by the author'. But perhaps the intertextual frames of the lay reader are insufficient to inspire the quest narrative in its inferential walks through the biomedical discourse. I took my own inferential walks in a range of clinical journals and medical texts, however, the brisk strolls took me into barren cul-de-sacs that offered little intellectual sustenance and even less inspiration to act.

While the DSM can be seen by the lay reader as a detached and rarefied medical narrative, it neatly reinforces the paradigmatic frame of the medical textbook. Macdonald (2002) observes that the medical text subscribes to a model or code that governs its linguistic practices. These codes are not part of a linguistic system, but are a symbolic system of meaning generated by the medical social system. Macdonald (2002) goes on to suggest that the medical textbook as a genre is most clearly identified through its lack of rhetorical features. This lack of rhetorical device then implies that its contents are self-evident and that its claims to validity can be unequivocally accepted.

Fisher (1991) suggests that in this relationship between medicine and society, doctors hold the dominant powerful voice by virtue of their exclusivity in controlling the bio-scientific discourse. She observes that Mishler (1984) calls for a 'more humanistic, patient-centred medical practice which includes both social-psychological and medical aspects of patient's lives'. However, one problem

with a more patient-centred discourse is that unlike the scientific voice whose traditions unite their stories in a single style, the pathographic voice lacks a unifying stylistic feature.

The emergence in recent times of the specific discipline of illness narrative or pathography has served to contest the biomedical account of the human experience of illness. Hawkins (1999) writes:

Pathography returns the voice of the patient to the world of medicine, a world where that voice is too rarely heard, and it does so in such a way as to assert the phenomenological, the subjective, and the experiential side of illness Pathography restores the person ignored or cancelled out in the medical enterprise, and it places that person at the very center. Moreover, it gives that ill person a voice.

The return of the voice to the person/patient not only restores a sense of balance to the illness conversation but it has also contributed to the ascent of memoir and autobiography as the emerging literary genre of the 21st century. Gilmore (2001) notes that while memoir was previously associated primarily with the lives of elder statesmen, it is now 'dominated by the young ... whose private lives are emblematic of a cultural moment'. She also goes on to note that the commercial volume sales of memoir have tripled in the last fifty years.

Most pathographies follow some variation of the narrative arc of the quest narrative. Propp (Ricoeur 1981) writes of the heroic quest that:

In these tales, a hero meets a challenge which he is sent to overcome. Throughout the quest, he is confronted with a series of trials which require that he choose to fight rather than to yield or flee, and which finally end in victory.

The sudden departure from this rose-tinted view of parenthood becomes a constant touchstone throughout the memoir until the validity of the preconceived notion of life as a parent is slowly drawn into question.

With the passing of each year since we began our journey of therapeutic intervention and personal transformation, Park's two memoirs, *The Siege* and *Exiting Nirvana*, eclipse both Maurice and Hamilton's memoirs in their narratives' lingering impact. The desperate language of hope combined with the forensic observations of behaviour and intervention, while compelling in those first moments of diagnosis, now seem slightly anachronistic.

Park's narrative style keeps the reader at a slightly greater distance from the minutiae of daily routines so distractingly prevalent in both Maurice and Hamilton and consequently delivers narratives that linger more poignantly in memory. And the biomedical texts that loomed so large as monoliths of immovable truth in my son's early days of diagnosis have eroded significantly. While their message has remained constant, the breadth of experience and miles travelled since allows my inferential walks a more panoramic vista.

Both the biomedical and pathographic discourses tell their stories with compelling voices, but the parental autobiographical narratives provide potent conduits for inspiration. While these damaged storytellers lack the universality of style or coherence of voice present in the biomedical text, their intimate stories connect at a deep level with fellow travellers. A discussion of the emerging dissonance between the evidence upon which pathographers underpin their truths combined with the authority they claim to tell their stories may provide useful insights.



In 1676 Isaac Newton wrote in a letter to his colleague Robert Hooke, 'If I have seen farther, it is by standing on the shoulders of giants'. While Newton in this instance was referring to his discoveries in optics, the quote has been used by the sciences ever since as a mantra to consolidate the role of evidence-based scientific research in building a brick by brick cathedral of knowledge. But the experience of the last ten years tells me that sole reliance upon the institutional monotheism of the scientific narrative is not enough. Information without the permission or power to act is not enough. The total absence of a social context in the medical textbook ensures a complete erasure of humanity in line with the guiding ideological principles of the biomedical voice. While the emphasis in scientific discourse must be to limit the opportunity for misinterpretation with neutral and exclusionary language, the absence of any other contextual description may serve to reinforce the reader's view of pathology without humanity, illness without impact, pain without feeling.

The glaring omission in the biomedical text for the lay reader is the absolute lack of empathy and social context. The lay reader could be forgiven for assuming the disorder under examination resides in the social and cultural vacuum of a petrie dish, free from the complications of human emotion. However, nothing is more pervasive and complicated than human emotion when addressing an infant with special needs. Unlike other disabilities, which may be diagnosed at birth or even in utero, autism's late onset leaves the parent unprepared for their child's slow and painful departure from their loving gaze to

destinations unknown. This late symptomological onset from unknown causes places the parental reader in a much more vulnerable space and therefore potentially more susceptible to influence.

For the readers of autism narratives, no single discourse can meet all of the emotional, intellectual and philosophical needs that empower or inspire the individual to act. From my experience the pathographic relational narrative, while lacking the empirical pedigree of the biomedical voice, gives parents of newly-diagnosed children hope and agency at a time when they have very little of either. This does not mean that the biomedical discourse is not extremely important and influential, because to act on the advice of desperate and emotional parents alone seems a dangerous leap of faith. On the other hand, I have a poem titled *Welcome to Holland* (Kingsley 1987) from a grieving mother describing the experience of grief, dislocation and hope following the diagnosis of her child with a disability taped to my study wall to provide me with agency and energy, not a chapter from the DSM.

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Author

Michael Whelan is an academic, writer, musician and autism advocate. In addition to his memoir, *The Other Country: A Father's Journey with Autism*, Michael also wrote the documentary film *What are you doing?* This educational film for school audiences on the topic of social inclusion and autism was distributed to every school in Australia and was screened at the United Nations in New York as part of World Autism Day activities in April 2013.

Through Autism Queensland, Michael developed and commenced delivery of Studio G, a post-school transition program for young people with autism. In July 2015, Michael joined Queensland University of Technology as an Associate Professor in Music in the Creative Industries Faculty where he continues his work supporting young people on the autism spectrum.

More than one way

There's more than one way to peel an orange.
 You could start with the pointy end of a knife,
 lick the juice from fingers, that sweetened accent,
 pulp on white paper towels absorb running words

you could start with the pointy end of a knife.
 Push it into skin, some thicker than others,
 pulp on white paper towels absorb running words
 cradled by your fingers, slice in wedges and peel.

Push the knife into skin, some thicker than others
 just deep enough to touch the flesh
 cradled by your fingers, slice in wedges and peel.
 Or you could dig in with fingernails raking

just deep enough to touch the flesh
 small jolts of orange to smell out your day.
 Or you could dig in with fingernails raking
 from the corners, pushing up flesh to mouths and teeth

small jolts of orange to smell out your day.
 Shave off skin for rind. Cut in quarters and freeze.
 From the corners push up flesh to mouths and teeth.
 It grew roots and recipes before this cutting on bench tops.

There's more than one way to start your day
 lick the juice from fingers, that sweetened accent
 filling your mouth with this everyday taste.
 There's more than one way to peel an orange.

CLAIRE ROSSLYN WILSON ,
 BARCELONA, CATALONIA/WINDSOR, VIC