As If You Have a Choice:

Autism mothers and the remaking of the human

P. N. Douglas
Abstract

This paper utilizes disability studies informed by feminist phenomenology to explore how contemporary representations of autism, and autism mothers, are integrally caught up in western (and now globalizing) understandings of health, happiness and the “normative” human. I examine the historical emergence of “autism mothers” as a new category of identity, and trace this alongside a global autism mother recruitment campaign to get at what’s “behind” this phenomenon. I argue that emerging autism mother figures like the feminine warrior are new and contradictory neoliberal subjectivities that contain a most “hateful” unethical and increasingly global duty: the reinscription and intensification of the “normal” human as bourgeois, nondisabled, white and western, and the “new” femininity as “naturally” nurturing and necessarily instrumental. Even more, these new subjectivities are governmental, operating as western colonialist translations of happiness, compelling compulsory participation in increasingly limited, violent, and globalizing frames of normative humanity for us all.

Keywords: Autism; maternal health; feminist phenomenology; disability studies
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I. Introduction

You didn't lose a child to autism. You lost a child because the child you waited for never came into existence [...] Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you.

-Jim Sinclair, autism activist, 1993

This paper arose out of my rather uncanny experience as an “autism mother” who has been both publically blamed for my son’s so-called threatening autistic behavior, as well as praised when he approximates normative frames of comportment. I wish to get behind the significance of this rather uncanny either/or blame/praise orientation to autism and mothering as one that has everything to do with the meaning of the human, happiness, health and love. To do so, I turn to the popular representation of autism as a key cultural scene upon which autism mother identities are emerging (on scenography see Butler 1993; Michalko 2001, 2002). I pay attention to one recent figure - the feminine warrior – as she appears within global campaigns against autism. With cultural theorist Stuart Hall, I understand such everyday cultural production as “deadly political,” entangled with questions of power, subjectivity and human possibility (Hall 1997, p. 290; also see Wynter 1992; Walcott 2003). Through several cumulative turns in the discussion, I argue that emerging autism mother identities like the feminine warrior “re-invent” and intensify a troubling form of contradictory neoliberal feminine subjectivity (Ringrose and Walkerdine 2008). Motivated by her fierceness, grief and love, this mother works for a future in which her child (and indeed the world) is free of autism, as an assurance of their future happiness and well-being. The embodied differences of autism transgress the normative human demanded in the context of late modernity: the self-interested, rational, autonomous and self-governing consumer subject (McGuire 2013). Already alluded to in my opening quotation, autism mother identities that grieve the loss of this subject and enact love through campaigns against autism thus contain a most “hateful” and unethical duty (Derrida 1995): the implication of an autism mother’s very love and identity in the normative violence imposed on transgressive bodies within western bio-medical, colonialist and global capitalist regimes (Rose 1999a; McGuire 2011a; Wynter 2003, 2006).1

1 There are parallels in my discussion to the Genesis story Derrida recounts of Abraham and Isaac. Abraham is summoned by God to sacrifice his only son Isaac, which he keeps a secret. This duty, which is an absolute duty, is a hateful one, though it must be born of love to remain absolute. Abraham’s action must both defy and uphold the human realm of ethics and...
Importantly, within the context of shifts in global health governance that now include partnerships with the global autism advocacy movement emanating from North America and the U.K. (Rosanoff, 2013), a universal and globalizing understanding of health is emerging. Resolutions and reports generated within the United Nations post-2015 global health and development process, for example, consistently identify “well-being” as the overarching health goal to be aimed for globally post-2015. Well-being is understood as the meaning of mental health itself, which includes not only the presence of “positive” mental states and “normal” coping, but the absence of autism and other “mental disorders.” Here, the consumer subject is again assumed normative, and autism and other mental disorders (understood in strict biomedical terms as disordered brain development) become a threat to the health, happiness and well-being of individuals, families, communities and nations. In fact, “mental disorders” now comprise an existential and economic “global burden” that calls for a global response: global systems of health governance that export western biomedical frames of normative identity, disorder, early intervention, prevention, recovery and treatment (World Health Assembly 2013a, 2013b). And this centrally implicates and demands a certain kind of mother-love and identity world-wide, one that fights against autism yet conceals heightening class and gender inequities that continue to cast women as primary care-givers (Ringrose and Walkerdine 2008). What’s more, within the United Nations process, health is now considered a fundamental human right. In other words, this version of health now includes the right to be free of autism (McGuire 2013), or, at least, to be as free of it as possible by western means, which again implicates a particular shape of “mother” the world over (United Nations 2013; World Health Assembly 2013b). This suggests that emerging neoliberal autism mother subjectivities are governmental, implicitly operating as western colonial translations of happiness, health and identity that link one’s very love and identity to global health and capitalist regimes (Rose 1999b; Foucault 1982). To go further, these new feminine subjectivities invite compulsory participation in increasingly violent and globalizing frames of gendered and normative human identity for us all (Titchkosky & Aubrecht 2009).

The movement of my discussion is an exploratory one. It unfolds in a circular fashion that deepens with each turn to gain greater analytic understanding of the phenomenon of autism mothers as an important, emerging area of study. I first provide a brief description of my approach as a feminist phenomenological one that also draws on post-structuralist thought and disability studies to show how “autism mothers” emerged on the western scene, and how they now operate within today’s popular representation. Secondly, I spend considerable time describing some of the historical conditions of possibility for the emergence of autism mothers to better understand how neoliberal subjectivities like the feminine warrior have come to translate and teach health, happiness and identity within western colonialist frames. Post-structuralist thinkers are particularly helpful here. Third, I offer a close reading and discussion of one global “autism mother” recruitment campaign (emanating primarily from white middle-class mother advocates in the US and UK) that employs the feminine warrior figure in a “call to duty” to mothers and allies world-wide in the so-called war against autism (on the cultural production of autism advocacy from within such war frames see McGuire 2011b, forthcoming). I will be particularly interested in describing how the language and affect of the campaigns implicates mothers in particular versions of subjectivity, grief and love, and I include, briefly, my own bodied response. To conclude, I ask what has become of the meaning of well-being, love, autism and “the human” through my journey here. Like disability historian Stiker, “At most my goal is to enlarge the understanding that we already have” (1999, p. 18; also see Titchkosky 2007, p. 19). In other words, there are responsibility at once – that of the uniqueness of the one in front of me – to retain its absoluteness (see Derrida, 1995, pg. 53-81). I engage with these notions of duty, love, hatefulness and ethics in relation to the feminine warrior mother figure throughout this paper.
already powerful stories about autism and autism mothers that circulate in our world. My aim is to enter and understand these stories differently.

II. Feminist Phenomenology: Reorienting towards a New Story on Autism

I begin with a very selective reading of phenomenology. Rather than proceed from the “natural attitude,” phenomenology “brackets” the taken for granted life-world of everyday life and instead takes the stance of a “perpetual beginner” (Merleau-Ponty 1962, p. xv; also see Husserl 1970, p. 142). A phenomenology of the social world seeks to reveal the ground of our taken for granted world in acts of interpretive consciousness that build up or intend a world of objects that “is ‘always already’ there before reflection begins” (Merleau-Ponty 1962, p. vii). This is a commitment to a rigorous kind of description rather than explanation. Through phenomenological description, the philosopher attempts to get close to the “essence” (Butler 1998, p. xi) of phenomena even as she acknowledges an excess of meaning that shimmers in an always-open horizon of phenomenal experience (Gerwitsch 1966, pp. 89-96; Schutz 1970, p. 96; Butler 1998, p. xi). Description then, is less a matter of “mental-image making,” though it may include this, than it is a creative act of interpretive consciousness intimately tied to a world of which it is a part (Merleau-Ponty 1962, p. xv; Butler 1998, p. x). It is this spirit of description I bring to bear as I attempt to tell a new story about autism and mothering.

Telling a new story about autism mothers involves bracketing meanings that emerge in the natural attitude. This is difficult. Autism and mothering are lived in a deeply affective register. Yet biomedical understandings saturate the sense of the life-world. In today’s context, it appears beyond question (and almost cruel to suggest otherwise) that because of her loss (the loss of her child’s normal and healthy development), a mother is grieving. Similarly, stories about mothers fighting against autism make sense to us – mothers must do so, and do so out of love, in order to give their child future happiness and success. Here, in the pragmatic use of because-of and in-order-to motives (Schutz 1967, pp. 86-96), the totalizing frame of the biomedical - animated by the unquestioned prestige of scientific sensibilities in the natural attitude – remains concealed. Bracketing the natural attitude reveals how our understanding of autism and a mother’s grief is possible at all, and exposes the apparatus of the “sayable” and “sensible” world (Titchkosky 2011, p. 73-6) within objectivizing biomedical terms that health regimes govern to produce well-being. Revealing the histories of interpretation that govern how meanings are produced will be the “pay-off” of the circular work of bracketing.

To do this work, I use the idea of the “backward glance” or “the behind” as a methodological orientation device. Ahmed writes:

To see what the “natural attitude” has in its sight we need to face an object’s background, redefined as not only the conditions for the emergence of the object (we might ask: how did it arrive?) but also the act of perceiving the object, which depends on the arrival of the body that perceives. (2006, p. 549)

Thinking with Ahmed, my own mother body figures as I turn and take a “backward glance” (2006, p. 570) to get at this mother’s background. This is not the temporal backward glance of everyday because-of motives, nor the future-oriented glance of in-order-to (Schutz 1967, pp. 86-96). It is instead a “peek” behind the increasingly familiar everyday images and language of autism and mothering. It is a “glance” that follows Ahmed’s “queer connection” between Husserl’s thesis of intentionality (i.e., only the object remains the same in acts of perception, a “changing same” that is at once there and intended), which I can not do justice to here, and the question of “the behind” or an object’s background – that which we must “conjure” (perceptually and in its historicity) in order for an object to appear (Ahmed 2006, p. 548-9). The question of the “real” meaning of autism will remain both unasked, and unanswered here. By uncoupling the “real link” between autism as biomedical and experiences of
meaning, histories of interpretation and possibilities for new interpretations might emerge. Autism returns only at the end of my journey, one that has given me a new “slant” (Ahmed 2006, p. 562) on autism, as it were: western framings of autism may in part be an accumulating effect of new neoliberal feminine subjectivities that are also acts of interpretive consciousness that tie happiness, health and well-being to the future “return” of normative human identity. I now turn to my journey of revealing these acts of everyday consciousness, beginning with a “backward glance” at the emergence of autism mothers.

III. Emergence: A Backward “Glance” at Autism Mothers

Autism mothers could scarcely have been imagined before the identification of “autistic disorders” by 1940s medical practitioners Leo Kanner and Hans Aspergers (for a detailed history see Nadesan 2005; Wing 1988, 1981). While autistic disorders had their roots in the mental hygiene and biological psychiatry of the early twentieth-century, mid-century neo-psychoanalytic approaches would quickly rise to eclipse these biological beginnings and place the blame for autism (and other troubled offspring) squarely on the mother (Nadesan 2005, p. 97-9; McDonnell 1998; McGuire 2011b). Indeed, since the mid-20th century rise of psychology as the expert discipline on “normal” childhood development, an ever-heightening medicalization of childhood and surveillance of mother’s and children’s emotional, social and intellectual lives has proceeded apace (Nadesan 2005, 80-1), all in the name of a child’s – and a nation’s - future well-being (Rose 1999a, 123; McGuire 2011b). Imagined within mid-20th century neo-psychoanalytic terms, the mother-child relation became the key scene upon which “normal” development unfolded (Nadesan 2005). A mother’s practices, emotional life and proximity to her child became tantamount: “The studies of Bowlby, Ainsworth and others fueled the claim that children’s mental health depended on mother love – and that mother-love meant being at home with your child” (Ladd-Taylor 1998, 14; also see Walkerdine & Lucy 1989, 59-61). Under the “paternalistic” guidance of (predominantly white, male, western) science, this shape of mother-love or lack thereof had emerged as both the originator of autism and “the regulator of the ‘normal’ development of the child and subsequent ‘healthy’ development of the state as a whole” (McGuire 2011b, 82).

While Kanner noted mothers in his autism studies worked outside the home and appeared “cold,” both he and Asperger retained a partly biological understanding of the origins of autism (Nadesan 2005; McGuire 2011b). It would take psychoanalyst Bruno Bettelheim to popularize and shift the burden of blame to mothers through the mid-century figure of the “refrigerator mother,” a cold, absent and disordered figure (Bettelheim 1967; Nadesan 2005; McGuire 2011b; Refrigerator Mothers 2003). Through his popularity in North America (on talk shows, in women’s advice columns) and his now highly criticized book (1967) The empty fortress: Infantile autism and the birth of the self, Bettelheim (who survived the Dachau and Buchenwald concentration camps) introduced parallels between the severe trauma responses he witnessed in Nazi concentration camp prisoners, and the rocking, repetitive behavior of autistic children. He theorized that, like the camp guards, mothers perpetrated grave harm through total indifference to their child, and initiated an autistic withdrawal of the self (Bettelheim 1967; McDonnell 1998; Nadesan 2005; McGuire 2011b). Apart from the intensity of mother blame, this birthed the very persistent popular and scientific understanding that the autistic child is suffering terribly, withdrawn into “a shell or prison (or camp) that incarcerate[s] an otherwise ‘normal’ or non-autistic self” (McGuire 2011b, 80; Bettelheim 1967).

Importantly, unlike other 20th century “bad mothers,” the “refrigerator mother” emerged as the ironically privileged subjectivity of North American, western European, white, educated, working middle-class women and children. Avenues of “improvement” available to “refrigerator mothers” (as extreme and paternalistic as they were) were closed to working class, Black, and other mid-20th century “bad mothers.” These mothers transgressed the bourgeois, white norm, and with their children came under a paternalistic and racist system of moral regulation (through categories of “mental retardation,” for example) that also implied racial and class inferiority (McGuire...
As one mother recounted in the *Refrigerator Mothers* (2003) documentary, “According to my doctor, my son could not be autistic. I was not white, it was assumed that I was not educated and therefore he was labeled emotionally disturbed.” As we shall see, while “autism” and “autism mother” remain privileged white and western identities today, perhaps one of the most significant and troubling shifts occurring in the present global health context is the push by autism mothers and advocacy organizations in the U.S and U.K., and by United Nations bodies to expand these western identities – and their subsequent biomedical treatment - to as many nations as possible world-wide (*Autism Speaks Global Autism Public Health Initiative* 2013; Rosanoff 2013; McGuire 2013).

With the decline of psychoanalytic approaches, the introduction of computer technology and the rise of cognitive and biogenetic approaches, understandings of autistic selfhood have been re-worked in ever-intensifying, universalizing and globalizing biomedical terms. During the 1970s and 1980s, cognitive psychology would first give us the metaphor of the computer to understand mental processes as the origin of behavior. Partnered with the emerging field of biogenetics, mental processes were irreversibly mapped onto brains, and the science of “normal” brain development became the *Zeitgeist* of our times (Nadesan 2005). The search for autism’s genetic cause (re)emerged, and technologies began to probe ever more deeply into the neurochemical workings of the brain (neuroimaging, for example). Ideas such as the “neuroplasticity” of the brain meant the “treatment” of autism shifted from the overt surveillance and remediation of mothers, to biomedical interventions (prevention, early intervention, pharmaceutical interventions, and behavioral therapies) (Nadesan 2005; McGuire 2011b). Parents and mothers in North America and western Europe were what McGuire calls a powerful “productive force” in this shift (and continue to be), forming (now global) advocacy organizations (*Autism Speaks*, for example) to promote biogenetic understandings and distance mothers from the condemning “refrigerator mother” figure (2011b). More recently, scientists of note have taken an interest in an “alternative biomedical model” (Nadesan 2005, 195). Also emerging in conjunction with the influence of mother advocates (*Generation Rescue* and the *Autism Trust*, for example), this approach turns not to genes but environment for causes: vaccines, antibiotics and polluted ecosystems, for example. Western advocates of this approach (like the feminine warrior) seek the world-wide “recovery” of “normal” and “healthy” children from autism through alternative biomedical interventions (i.e., diet, cleansings) (McGuire forthcoming; Nadesan 2005; *The Autism Enigma* 2011). While the site of the “causes” of autism may have changed with biomedical approaches, the existential meaning of autism as a suffering, otherwise normal child threatened and trapped by autism, remains remarkably the same since Bettelheim.

Now under the cloak of a global epidemic, cultural appearances – and disappearances – of autism mothers betray a new urgency to achieve a normative identity and “well-being” within our contemporary moment. Something new has been added to an age-old adage. The good/bad mother and the achievement of normalcy is now mediated by autism but also by an intensifying, contradictory feminine saturated in the language of affect (love, grief and hatred of autism), instrumentality and duty. Mothers do, after all, give life, including autistic life, and are assumed to be primary care givers (O’Malley Halley 2011; Ladd-Taylor & Umansky 1998). Yet while mother-love and identity continue to take shape as the “regulator” of normal development and the deliverer of an autism-free future, the approach to this duty has changed. Within the terms of biomedicine, a mother must learn to be ever-vigilant for earlier and earlier signs that may indicate a problem with her child’s development, as well as for possible external hazards (i.e., maternal age, vaccinations, and toxins). In her nurturing and proximate stance, she must be ready to intervene and love with a rational instrumentality, guided once more by a predominately male and paternalistic bioscience (Rose 1999a; McGuire 2011b). In other words, normalcy has become the achievement of a contradictory feminine figure who is not only loving and ever-watchful, but also self-governing and instrumental

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2 It is important and troubling to note, however, how the “chilly” mother seems to haunt contemporary research agendas (Grinker 2007).
Surveillance, too, has shifted from external experts to the mother herself and even further inward, to a mother’s own self-governance. In this way, I suggest, biomedical frames coincide with an intensification of a mother’s culpability - this time in the language of prevention, early warning signs, early intervention and recovery (Sousa 2011; Blum 2009; McGuire 2011a, 2011b).

Biomedical understandings of autism, and autism treatment, have exposed a mother’s inner life – her choices about biomedical approaches, genes and biological states – to scientific regulation in newly intensifying ways. Autism mothers are now at once both positively and negatively culpable for their child’s autism, often at one and the same time. To state this new autism mother subjectivity in good/bad mother terms, first, as negatively culpable for her child’s autism, the “bad” autism mother appears as a kind of “symptom” of disorder and pathology. Whether by virtue of her own disordered biology (genes, antibodies), suspect morality (the “wrong” biomedical choices about vaccines or age to have children) or emotional/mental disorder (biogenetic depression), this mother is out of control. In her bodied disorder, she “causes” autism and its continued threat to our global well-being. In the journal *Pediatric Neurology*, for example, Connor et al begin with what might be considered a question of bodied disorder, querying whether maternal serotonin levels are “too high” or “too low” and therefore causally link a disordered maternal body to autism in the very premise of their research question (2006; also see, for example, Myers, Mackintosh and Goin-Kochel 2009). “Autism mother science” such as this finds its way into ever-expanding media reports about the latest genetic link to disordered mothers or the “right” maternal choices (Murray 2008; Jones & Harwood 2012; Clarke 2012).

Secondly, as positively culpable for the “right” interventions and for her child’s recovery (or at least their “improvement”), and “naturally” moved through love and grief, the “good” autism mother undertakes inhuman feats of advocacy and relentless treatment regimes to rid her child of autism. Sexy, successful, loving and instrumental, she is an agent in control of autism and their future well-being, the governance of which I discuss later. Actor, author (see McCarthy, 2008) and current president of *Generation Rescue* (2013), Jenny McCarthy is an example of this contradictory and intense cultural figure. Her message is one of recovery at all costs, and she is using her celebrity to spread the message globally. It is important to note that autism mother representations are not always this dichotomous or extreme – completely good or bad – nor that there are not times, like all bodied beings, that our children suffer and require intervention. Yet there is much to learn from considering these hyperbolic new forms of the feminine and their translation of western biomedical versions of health, happiness and normative identity in the form of a contradictory feminine, a “suffering” child and an unethical duty – to eradicate the unique difference of the child in front of her – within their very constitution.

IV. Appearance: The “Backward Glance” of Perception and the Feminine Warrior

Through the historical backward “glance” of the previous section, I drew the seemingly natural link between autism, disorder and suffering on the one hand, and mother-love, the achievement of normalcy and future well-being on the other, into question. With these layers revealed and this background in mind, I take a “second look” at the autism mother’s background through an in depth examination of one specific example – that of the feminine warrior. I consider a global autism mother recruitment campaign and my own response to it to ask questions about how seemingly natural ties come into being over and over again in ordinary acts of everyday interpretive consciousness. I then ask what the doing of my description suggests about how these ordinary acts unfold and achieve their effects. It is my hope that by asking questions of perception, I might also show how there is nothing “natural” about the meanings we make of autism, and autism mothers, within the everyday meaning-making backward glance of perception.
Autism Mothers Global Recruitment Campaign part one

I sit with laptop on knees and browse The Autism File Global website, the first “hit” when I google “autism mother.” This is a widely read print and online magazine (now with its own media channel, facebook page, and twitter following) that was founded in 1999 in the UK by autism mother, Polly Tommey to offer “information and support” to new autism parents. There is one image of an autism mother campaign that captures me. This particular image appears at the center of the cover of Issue 33 (2009) of the Autism File Magazine with twelve other similar photos and a headline in the bottom left corner that reads in bold “AUTISM MOTHERS UNITE WORLDWIDE.” In it, six figures who appear white and female with long brown or blonde hair stand posed in a line, most angled in and toward one another, one facing away. Each wears the same uniform of long, black evening gowns with low necklines and high heels. Their stance is wide, like they are ready for action. They appear slim and “fit” and stand tall, their necks long, bare shoulders thrown back. No one smiles. Hands are on hips, and one gloved hand holds its partner, presumably just taken off. The silky, elbow-length gloves are vibrant red, green, purple, silver and yellow. The image now appears as part of a photographic archive on the Autism Mothers facebook page linked from the magazine’s site, alongside other images of groups of autism mothers from England and the United States, though there are groups from South Africa, Dubai and New Zealand too. I come across a similar image of the same mothers in a newspaper article, and learn that the photo shoot had been done for the United Nations World Autism Day (O’Brien 2009). Something stirs in me. Grief? Horror? Recognition?

Autism Mothers Global Recruitment Campaign part two

In my search, I come across more of the same images in an Autism File video linked to the same magazine through their facebook page (these images also appear in an Autism Mothers calendar, on tote bags, keychains and mugs). I am beginning to “get the picture” of a far reaching, multi-media campaign “[…] to bring mothers of autism together across the world” (Autism Mothers the Final Cut 2009). I find copycat videos made in other western countries with similar stories, as well as other campaigns that use this feminine warrior image. In this particular video, dozens of images of mothers in some version of the black gown pose ready to run, and ready to fight: some have boxing gloves on or hold racing flags, others pose in “Charlie’s Angel’s” style or stand with motorcycles, ready to race. A forceful statement follows the images: “Autism mothers, a powerful alliance. Standing together, fighting for our children. We will win. We will win.” The images are set to the Leona Lewis version of the pop band Snow Patrol’s song Run. The song starts slowly. Its haunting progression builds to inspirational peaks with lyrics that might very well have been written from the feminine warrior to her autistic child:

To think I might not see those eyes, makes it so hard not to cry […] Light up, light up, as if you have a choice […] Even if you cannot hear my voice, I’ll be right beside you dear […] Louder, louder, and we’ll run for our lives. (emphasis added) Snow Patrol, 2003

I watch the video over and over again, mesmerized by its drama. The words, images and music haunt me and return to me at unexpected times – driving in my car, walking up the steps in the home where I live, shopping for groceries. I search these images, looking for something, scanning the poses and determined expressions. These mothers know something, I think, and part of me knows it, too. It is this violent, unethical secret they keep that seems to bind them together, and them together with me. I struggle with grief at this figure, and with outrage. I find the campaign exhausting.

I now have two descriptions of my experience with two different iterations of a global autism mother recruitment campaign. One appears on the cover of a popular UK autism magazine, the other takes the form of a YouTube video. Both use language and images. Both are widely available through virtual worlds. The campaign is global in reach – and globalizing - as it makes the now familiar, almost taken for granted call to join the fight against autism. The call emanates from autism mothers of the US and UK, summoning mothers “across the world” to join the fight. Like the World Health Assembly resolutions and reports to follow (2013a, 2013b), it globally exports
western biomedical and illness/recovery frames of autism as only and always a problem body/brain and worse, as a threat to the well-being of children, homes, families, nations, and indeed, the world (McGuire forthcoming). Within its biomedical frame, the recruitment campaign involves a call to mothers that is also a duty. After all, according to western frames, a mother’s nature – her calling – is to bear, love and protect her child in a particular shape of mother-love as we saw above. And this child has been taken by autism. This mother’s because-of and in-order-to motives are clear. Telling a different story about autism and mothers requires a reorientation away from depictions of autism as a problem or threat, and toward autism as a cultural scene – a background - upon which the troubling and contradictory feminine warrior is emerging (McGuire forthcoming).

**Autism as a cultural scene – moved through affect**

The Merriam-Webster dictionary online defines a campaign as “a connected series of operations designed to bring about a particular result” (Campaign, 2013). The global autism mothers’ recruitment campaign, which began in 2009, consists of a widely distributed video and images linked to a facebook page, twitter page and magazine issue that continue to be virtually accessible. It was and is similar to other global autism mother campaigns like that of Generation Rescue (2013). And it continues within regular features on advocacy (news from the front!) and “biomedical updates” in Autism File magazine (2013), suggesting that this is an ongoing fight, one with duration, one in progress, one that needs particular types of mothers in order to make a particular kind of progress – an autism-free future that will allow for individual and collective well-being and economic flourishing. Mothers, clearly, are the campaign’s operatives, its subjects and actors. Indeed, the campaign needs mothers to act in this new warrior-like way to succeed. The sought after result is clear: “[…] to bring mothers of autism together across the world […] a powerful alliance standing together fighting for our children […] we will win.” With the massing of warring mothers “across the world” who now uniformly orient to autism as a threat, this most powerful force “will win” the fight. We are “fighting for our children,” the campaign declares. The alternative, it suggests, is the tragic loss of our children and the failure to make the right kind of progress toward a future free of autism.

The campaign orients its viewer – mothers and allies – through affect and the play of powerful contemporary narratives – a terrifying threat to a child’s well-being, a mother’s love and grief, and the courage of a hero-warrior. Despite myself, I found myself “captivated,” “mesmerized” and even “exhausted” by it. The words, images and music “occupy” me. I “search” the images for “something.” I remember my own struggles with my son in the everyday and feel bound to these mothers. The campaign is personal and it betrays urgency: “Even if you cannot hear my voice […] we’ll run for our lives,” sings Lewis. Hundreds of mothers abandon their “natural” place as proximate to their own child so that they might promote it. We know that they will return here, alone in the face of this terrifying threat. How do these narratives operate on and with viewers here?

Within the campaign, an orientation of affect moves and implicates viewers (mothers and allies) in the fight against autism, and toward normative versions of the human and well-being. Indeed, the campaign makes its “impression” through affect, reshaping the very shape and direction that our embodied subjectivity might take (Ahmed 2004). In other words, the campaign’s use of affect – love, terror and grief - is operative in making us subject to, and subjects of this new contradictory feminine subjectivity and her unethical duty. “There are two meanings of the word “subject,”’” Foucault states, “subject to someone else by control and dependence; and tied to his own identity by a conscience or self-knowledge” (1982, p. 781). Let us leave Foucault’s first meaning aside for the moment, and instead concentrate on his second meaning (perhaps in a way he may not have intended) - “tied to his own identity by a conscience or self-knowledge.” This implies that we come to know ourselves as subjects through identity as a particular, and embodied, historical possibility. Like the tie that binds us to the autistic life we bore, mothers are paradoxically tied to this historical identity by a so-called nature given duty to protect our child from threats like autism. This duty is understood as outside of time even as it shapes time through particular actions toward our autistic child’s purported future well-being. Who decides what shape this well-being takes? How do I
turn away from the autistic life in front of me?

To press the point of becoming subject further, I suggest that the orientation of affect within the campaign invites and even compels – mothers and allies - to take a backward “glance” of perception of our own. It turns us toward memory and the familiar, taken for granted ground of the everyday life-world that includes particular understandings of mother-love, autism and well-being, as we have seen. We are called to “know again” a particular type of mother and a particular type of threat – a mother-hero in the shape of the feminine warrior fighting against autism. Ahmed describes this interpretive move of perception in reference to Althusser’s (1971, p. 163) notion of the ideological recruitment of subjects, “The subject is recruited by turning around […]” (Ahmed 2007, 157). In this case, recruitment, through powerful narratives and compelling affect, operates (now globally) within the campaign to re-orient mothers and allies toward western biomedical understandings of well-being that necessarily work for the elimination of autism (McGuire 2011b, forthcoming). In other words, the feminine warrior – through her “natural” love – is not only a new identity category but also an orientation, an instrument of and instrumental in emerging regimes of global health governance that seek to achieve identity through western biomedical frames.

Judith Butler’s work on gender constitution suggests that it is through repetition – knowing/doing ourselves, and knowing/doing ourselves again – that identity becomes an historical, embodied possibility (1997, p. 403). Through the campaign’s various iterations (alongside other similar campaigns and popular representations), the autism mother, this time as feminine warrior, becomes a familiar identity. Ironically, it is through Foucault’s first meaning of subject as an historical situation of constraint – “subject to someone else by control and dependence” – that we might become a particular type of autism mother who knows herself, recognizes herself, and turns to act in the world. My freedom to act – my subjectivity - is paradoxically formed in this situation of discursive constraint and authority. To loosen the hold of the feminine warrior subjectivity a little further and open new interpretive possibilities (new directions to turn) for other historical iterations of autism mother, I turn next to the role of language in world-making, both within my description and within the campaign (Butler 1997, p. 402-4).

The Role of Language

Fleshy words saturate my description and discussion of the campaign thus far – words like captivate, secret, stir, haunt, touch and outrage. What might this disclose about subjectivity and my activity here? How might this help me to tell a new story? First of all, my activity of description is much more than the doing of “mental image-making.” An object cannot be familiar, grieved, stirring, outrageous, or captivating without ties to the background - some kind of proximity to or touch of bodies, histories and language. These words elicit a living, touching, feeling experiencing body-subject. They betray an intimate relationship of body/subject and word/world. As Butler phrases it, this relation to and knowledge of the world is one of “kinship” steeped in language. Following a basic phenomenological principle, she says “Consciousness is always consciousness of its object, it is nothing without its preposition, and its preposition marks its kinship with the world that it interrogates” (1998, p. x; also see Merleau-Ponty 1962). Description, and subject-making, involve acts of consciousness that build up a knowable world, yet know this world intimately as one that can only ever be done through the instability and openness of language. Body-subjects do not “stand alone” but become, “gearing” into the world as well as being moved by it (Schutz 1970) in a relation of touch and proximity to and with their inseparable object.

Furthering my point, and moving now more directly toward the “feminine” and “warrior” language of the campaign, I want to think about how the viewer is presented with campaign language that appears in direct correspondence with the “real” of the world. For example, body and world are separated in the campaign’s images: autism is a “threat” external to history, and “mother” its natural “warrior.” The interpretive schemes surrounding autism and mothering (i.e., western, biomedical) that tie us to particular, and embodied, understandings of “types” of people, in this case of problem types, simply become part of the scenery. They fade away into the background. But objects – campaigns and identities – cannot be recognized or oriented without these already constituted, and constituting, interpretive schemes. We are all caught by a language that renders invisible the processes that make the “real” (autism, feminine warriors) appear as if it is an empirical given (Schutz 1970). Rather than the sacrifice
of human difference to normalcy, the threat of autism, and its corollary, the heroic feminine warrior autism mother, is what’s “real” here. Taken-for-granted interpretive schemes keep this mother’s secret well hidden, tucked away in a background that easily fades from “view.” Through its language, we are oriented to the campaign’s meaning as a closed matter, and to consciousness as separate and internal, a disembodied, unremarkable thing in and of itself.

If we stay with the idea that language is a world-making activity, then what might the images and language of the autism mother campaign itself teach us about the feminine warrior as a “reinvented femininity”? First of all, this autism mother is no longer Bettelheim’s refrigerator mother. This mother is “hot.” Her uniform is not that of the soldier, but a softer, feminine, sexualized one. Her feminine curves and flowing hair are accentuated by her black gown and high heels against white background. She is exposed, vulnerable, even physically compromised in her evening gown and heels. She could not “run for her life” here. What’s more, the very strangeness of the formal black gowns suggests something extraordinary is going on here. By western significance, this autism mother is very formally, and publically, grieving. At the same time, she is courageous, strong and independent. Head held high and shoulders thrown back, she stands not delicately but proudly. She is empowered. Unlike the hesitant feminine corporeality Iris Marion Young depicts, one that shrinks in space, the feminine warrior occupies and even extends into space (1980). Her hands are on hips and her stance is wide. She does not smile or look away but looks straight at the camera as if she might spring into action. Her gloves are literally, coming off. Yet even this gesture of strength and aggression is encased by softer, nonthreatening, sexier qualities. Her gloves are silky and long. Her bare shoulders meet cleavage. Here, characteristics of the feminine and the masculine mingle. They contradict.

The violence of the campaign’s language and images is ironic given western notions of bourgeois, white femininity and motherhood as caring, sensitive and nurturing (Ringrose and Walkerdine 2008). The campaign seems to contain some contradictory messages not only about gender but also about that most sacred, loving and close of bonds: that of mother and child. A (birth) mother carries and must cut free the infant she births. She is that close to her child. This tie, one that binds mother to child/child to mother is understood as timeless, situated in biology and therefore “natural.” It is only natural then, that mothers are protective and nurturing of the life they give. This certainly appears to be true of the feminine warrior. Her willingness to protect her child and family from the supposedly hostile threat of autism is unsurpassed. She is willing to go to war and by implication abandon her child (indeed, no children appear in the campaign) and even lay down her life or the life of her child to win this fight. Witness the murder-suicides that mark media reports over the past number of years (McGuire 2011b). When it comes to autism, the closeness of the mother/child bond, paradoxically, demands distance. Her aggression and hostility (she is, after all, fighting a war), qualities more commonly associated with masculine subjectivity, and thus contradictory ones, remove her from the close and loving bond of the feminine. So while she operates in the feminine and affective (she is loving and nurturing), she also operates in the masculine, instrumental, logical and hostile. This fight must be waged, at least in part, through a mother’s hostility toward her autistic child, one paradoxically borne of her love (Derrida 1995). While she is physically proximate, she is fighting against a threat that is personal, one located in her home and even closer, in her child’s body (McGuire 2011b). There is no “backward glance” here or hesitation at the loving and paradoxically violent, unethical duty with which she is charged. The images of the campaign betray only determination and courage.

The New Feminine

Autism mother subjectivities (feminine warrior, hero-warrior, westernizing autism mother) are “reinventions” and intensifications of neoliberal and postfeminist discourses of the empowered feminine. Ringrose and Walkerdine (2008) argue this is a contradictory neoliberal subjectivity in which qualities of the masculine and the feminine combine and contradict, as we have seen with the feminine warrior above. Success and independence outside of the home meet success in the achievement of innate feminine qualities: beauty, allure and nurturance. Notions of beauty adhere to western bourgeois standards: this warrior is slim, fit, white and flawless. There are no
drug-store bleach-blonde dye jobs here, no fatigue from domestic labor and no shortage of resources, whether financial or temporal. She is liberal feminism “all grown up.” Like the neoliberal, postfeminist “yummy mummy,” the feminine warrior “has it all” – kids, career and beauty. But more, this mother must accomplish all of this, and go to war. She is not only the alluring feminine object but also an exaggeration of the masculine agentic subject. She must be both distant and proximate simultaneously. The feminine warrior autism mother thus not only intensifies the culpability of autism mothers in terms of “cause” and “cure” through love and proximity, she intensifies Ringrose’s and Walkerdine’s empowered feminine subjectivity (2008).

Neoliberal discourses (whether as ideology, policy or forms of governance), articulate and incorporate the marketization of every aspect of human life, whether the governance of the market, social institutions or indeed, how we understand and do our selves (Larner 2000). Under neoliberal governance regimes, the ideal self is the self-entrepreneur. In a globalizing consumer capitalist society, this means that owning the “means of consumption” as a way to “consume ourselves into being” has become the route to ultimate freedom, well-being and happiness (Ringrose and Walkerdine 2008; Rose 1999a). We have become our own experts. What does the feminine warrior consume? Beauty products, fashion items and items of fitness, to be sure. Perhaps internet websites, parenting books or counseling, too. But there is more. The feminine warrior must not only consume herself into being as sexy object/commodity, and agentic mother/career subject. She must also learn to be an effective, successful warrior, and as such she must consume her autistic child into being as non-autistic. Bio-medical interventions, behavior therapies, parenting tips, autism therapies and endless information (scientific, bio-medical, environmental or otherwise) must be on her list too. They are her weapons. She is the ideal feminine and more, an intensification of “[…] an intensification of the feminine as (both subject and object) of commodification and consumption” (Ringrose and Walkerdine 2008, p. 230). Hers is an impossible task to negotiate: she orient’s through love and hostility simultaneously to eradicate the autistic child who persists in front of her. “Failure” haunts this contradictory femininity (it is impossible to achieve). Yet when failure inevitably occurs, or “progress” is slow, it is cast in the individual, psychological and pathological terms of neoliberal discourse (Rose 1999a). Still, it is only more therapies are needed! More rallies of empowerment! Reinforcements! Ringrose and Walkerdine tell us that the ideal feminine is “bourgeois yet coded universal, normal and attainable for us all” (2008, p. 228). In this way, neoliberal discourses masquerade as our “freedom” and “happiness” while gender and class inequities deepen and intensify, leaving transgressive bodies to fail in the achievement of the ideal self, let alone in its exaggeration: an autism mother who is responsible for ushering in a future of individual and global well-being necessarily autism-free.

V. Conclusion

If translation is governmental, as the work of this paper suggests, it is also, and importantly, ethical. Not only do emerging and contradictory autism mother subjectivities translate western biomedical patriarchal consumer capitalist and colonialist regimes into globalizing versions of mother-love, identity, health and well-being that capture our hearts and imaginations. They also transpose an instrumental orientation that conceals such inequity along with a violent and unethical duty – to eradicate the unique autistic life in front of me - into their very historical constitution and everyday appearance in acts of perception. These figures and their “background” are compelling. They trade on the prestige of science and mother’s “natural” love, duty and alarm. And they accumulate meanings about autism (and thus change autism’s meaning) in their work as translations, ones that seem only to intensify both a mother’s culpability and the suffering, threat and disorder found in the “original” autism science and industry behind their very making (on translation, see Benjamin 1968).

It has been my aim here to enter these stories about autism mothers differently and “enlarge” (Sticker 1999) our understanding of the stories already being told about autism, mother-love, “health” and the normative human. My trajectory has been exploratory. By bracketing taken-for-granted sense-making motives and biomedical understandings of the human, I have gained a deeper analytic understanding of the phenomenon of autism mothers, suggesting further study. To conclude, I want to return to the question of what has become of the meaning of autism
through the telling of this new story. If there is nothing “natural” about autism, autism mothers and the meaning we make of them, then the phenomenon of autism and autism mothers has become an invitation of its own. Rather than turn away, it is perhaps in turning toward and being-present-with the embodied difference of autism (indeed, all embodied difference) – with the complex histories, identities, acts of perception, suffering and happiness that mark the human journey differently for us all (Ahmed 2010, p. 12) – we might learn something new about love and the meaning of human flourishing.

Acknowledgements

I am both grateful to my son for his permission to write, and keenly aware of the complex power and ethics involved in narrating our life together. I do not write to tell the “truth” about his personhood, but to expose the cultural sense that pathologizes and governs us both. I would also like to thank Anne McGuire, Tom Reynolds and Tanya Titchkosky for their thoughtful readings of this paper.

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