Disability and Genetics:
Affirming the Bare Life (the State of Exception)*

JAMES OVERBOE Wilfrid Laurier University

This essay argues that "expressions of life" of disabled people are both marginalized and nullified through geneticism. Underscoring the application of genetics is the continuum from liberal individualism to nostalgic populism. Drawing from the work of Judith Butler, the paper outlines an ableist matrix. Giorgio Agamben's observations about bio-politics—a distinction between the "bare life" and the "political life," with disabled people primarily associated with the former—denotes a restrictive humanism. How disabled people negotiate the privileging of political life over the bare life is illuminated through the concept of "normative shadows." The paper discusses how to affirm expressions of life of disabled people through the essay Pure Immanence: A Life by Gilles Deleuze.

GILLES DELEUZE PREFERRED THAT HIS WORK BE USED, not analyzed. From a sociological perspective, this paper traverses and uses various paths to argue that "genetic fundamentalism" negates "expressions of life."

* This manuscript was first submitted in September 2006 and accepted in December 2006. Contact: joverboe@wlu.ca.
deemed disabled. Moreover, this essay argues for the affirmation of “expressions of life” that have been negated as “states of exception.” Applying Giorgio Agamben’s theoretical views on life to the concept of disability, I argue that disabled lives exemplify what is meant by the “bare life” (associated with the state of exception) as opposed to the “political life” linked primarily with being able-bodied. This distinction will attempt to explain a public discourse that favours a non-disabled orientation towards the social world and questions the authenticity of the experience of cerebral palsy. Next, the conflation of liberal individualism and nostalgic populism is critiqued for justifying the negation of (possible) “expressions of life” through “genetic fundamentalism.” The following section addresses the dominance of the discourse of genetics in any discussion concerning life. Drawing on the work of Judith Butler, the next segment argues that there is an ableist matrix that constitutes the disabled “expression of life” as negative. The paper concludes by offering an alternative view that affirms “disabled” “expressions of life” through the Deleuzian concept of “Pure Immanence.”

Disability as a “Bare Life,”
Which Is a “State of Exception”

The title of this special issue, Genes and Society: Looking Back on the Future, resonates with me. On September 28, 1997 I was forced to look back on my own genetic make-up (as some other people perceive it) to critique the future. Listening to the Canadian Broadcasting Corporation radio program Cross Country Check Up (Murphy, 1997), I heard a geneticist claim that he had “discovered” the genetic cause for cerebral palsy. Over the years, my physicians have concluded that my cerebral palsy was caused by a lack of oxygen to the brain. This new genetic explanation is a pre-cursor, and reduces the “lack of oxygen to the brain” to a complication resulting from genetic mutations. Consequently, my body and my life are now being read through the lens of genetic fundamentalism.

Provoked, I felt compelled to respond and called the program. In my interview, I explained that the question “When should we screen for genetic defects?” devalues the experience of disability by presuming that genetic intervention is not only permissible but preferable in certain cases. In terms of so-called genetic abnormalities that may cause illness and disability, “common sense” would suggest that some intervention is not only desirable

1. Throughout this paper, I will use the terms able-bodied, disabled and embodiment, but I do not want to infer that my analysis is restricted to physical disabilities. Often my cerebral palsy is equated with a lack of intelligence, or a lack of emotional equilibrium, cognitive problems, or a psychiatric diagnosis. Therefore, for the purposes of this paper the term disabled is used in the broadest sense and can refer to psychiatric, developmental and sensory disabilities as well as physical. Similarly, the terms non-disabled or able-bodied are interchangeable and privilege an aesthetic and sensibility that negate the “expressions of life” of people who are considered to be sensory, cognitive, physical or psychiatrically disabled.
but is a societal goal. I spoke about the positive aspects of my cerebral palsy, stating, “not in the sense of a ‘gift’ from which other people learn, or as God’s chosen ‘crippled angels,’ but rather how my spasms give me great joy and how they inform my life. Any success I have is not despite my cerebral palsy but because of it!”

I also argued that these positive aspects of cerebral palsy cannot be “measured,” because the ways and means of measurement are developed from the perspective that devalues cerebral palsy as an “expression of life.” I spoke about the similarities between myself and Tracy Latimer, who was murdered, to forestall the invocation of a continuum of cerebral palsy with myself at the pinnacle (the poster-child for overcoming) and Tracy Latimer (symbolizing victims) shackled to the lowest rung in life and memory.

As my segment concluded, the host, Rex Murphy, thanked me for educating him as well as others. I corrected him, stating, “My intention is not to educate others but to give cerebral palsy a life-affirming presence. I explained that my life is not, and should not be, dependent upon able-bodied people understanding me or giving me their blessing.” Often people who privilege an able-bodied life have demanded an explanation for my being alive. Today, by having a presence, I conveyed to the audience that no longer did I have to explain, justify, apologize for, or educate others about my cerebral palsy. The radio segment offered me another opportunity to expose the vivaciousness of cerebral palsy as a life affirming force. Consequently, I am moving beyond the dichotomous pairing of disability and ability which restricts my vivacity.

Since I was a disembodied voice over the radio, ableist rhetoric and anger could be vented. One caller screamed, “How dare you question normality!” Others said that I should be thankful they allowed me into a regular school and I repay their generosity by making such outlandish statements. No matter what I said, the ableism was pervasive. Believing that I was too intelligent, some callers questioned my ability to comment on the lives of severely disabled people. Others maligned me for being outrageous and lacking rational thought. Paradoxically, I was either too intelligent or too stupid. Either way, the status quo which favours the body and lives of non-disabled people remains intact.

The theories of Giorgio Agamben allow me to explore the underlying principles that inform this discussion on genetics and disability. Giorgio Agamben (1996: 30) argues that “the concept of people does not refer to a unitary subject. It is an oscillation between two opposite poles: People as a whole refers to an integral body politic whereby life becomes politicized. And people as a subset a fragmentary multiplicity of needy and excluded bodies.” Agamben (1996: 30) adds, “The concept of people pretends to be inclusive with no remainder. While simultaneously an exclusive concept known to afford no hope.” At one extreme, people were anointed to the total state of sovereignty, at the other end, total banishment. These banished people are considered to be under the “state of exception” (Agamben, 1998: 26–27).
For the majority of the radio audience, I personified the extreme binaries of the concept of people by being anointed to the total state of sovereignty while clinging to aspects of my life that should be banished as the "state of exception." More disturbing for the audience was my privileging of "my expression of life," which flowed from my spasms over other expressions associated with able-bodiedness. My point in affirming a disabled expression of life is to give it a presence. Ironically, by giving voice to a "disabled expression of life" and noting its significance within the polis, I unwittingly reinforced my stature as a "bare life" by speaking "madness" worthy of my being banished to the "state of exception" by the majority of the listening audience.

Tracing within modern society, where sovereign decisions give life and pronounce others "not worth of living" coincide. Within modernity, the line between biopolitics and thanatopolitics has been blurred, and there is a movement towards an "ever more intimate symbiosis not only with the jurist but also with the doctor, the scientist, the expert, and the priest" (Agamben, 1998: 122). The symbiosis between the sovereignty and physicians in the decision-making of what constitutes "a life not worth living" is a thread that extends through the eugenic movement to the present discourse on genetics.

Researching the extermination of psychiatric patients and disabled children during the Nazi Regime, Proctor (1995: 172) writes, "Euthanasia took on less the character of a single Reich-wide 'operation' and more the character of normal hospital routine. Equally disturbing is the fact that doctors were never ordered (emphasis in original) to murder psychiatric patients and handicapped children they were empowered (emphasis in original) to do so, and fulfilled their task without protest, often on their own initiative." In this genetic age, David Le Breton (2004: 5) asserts, "The identification of a genetic illness which is currently untreatable leads potentially to the decision to carry out a therapeutic abortion, and in this way a drift occurs, whereby medicine moves away from a therapeutic role to the project of eliminating that which it cannot treat." The Critical Art Ensemble (1998: 125) add, "To be sure, once eugenics is perceived as a means to empower the child and the parent, it loses its monstrous overtones, and becomes another part of everyday life medical procedure. Capitalism will achieve its goals of genetic ideological inscription, while at the same time realizing tremendous profits for providing the service."

The radio audience had to make sense of my position as simultaneously exemplifying sovereign status through autonomy while embodying a spastic "bare life." My status as an academic allowed me "sovereign status" while, simultaneously, my insistence on affirming the vivacity of my spasms was a constant reminder to them of my status as a "state of exception." Upon my birth, I epitomized "the wretched" and "the vanquished" excluded from the "political life." By attaining the status of an academic I am able to be included into the realm of "political life." From the perspective of the
radio audience, I had a life “worth living” or in Agamben terms a “political life.” The expression of life associated with my cerebral palsy (the bare life) had no meaning for them, except as a “state of exception.”

The Search for the Holy Grail and Genetic Fundamentalism

The search for perfection in society is not a new phenomenon; Lennard Davis (1997b) argues that during pre-modern times, there was this notion of the ideal body that was unattainable for the common people, who were called the “grotesque” because of their imperfect bodies. Davis (1997b: 11) asserts that the “grotesque permeated culture and signified common humanity, whereas the disabled body, a later concept, by definition was excluded from culture, society, and the norm.” Michel de Certeau (1984: 139) points out that from birth to death through written words norms are set that define the boundaries not only of the proper behaviour of the body but also of the body itself. Today, “genetic fundamentalism” has shifted the setting of norms and boundaries by the written word from birth to pre-birth.


In their analysis of the effects of genetic engineering on race and gender, Dorothy Nelkin and M Susan Lindee (1995: 387) argue, “The gene in popular culture is not a biological entity. Though it refers to a biological construct and draws its cultural power from science, its symbolic meaning is independent of biological definition.” Similarly, Ruth Hubbard (1997) argues that the symbolic meaning for genetic perfection in popular culture is not based upon a biological entity; it draws its cultural power from a science that devalues a disabled “expressions of life” (Kallianes and Rubenfield, 1997; Davis, 1997a; Davis, 1997b; Wendell, 1996; Morris, 1991). James C. Wilson (2002) and Richard Lewontin (1995) claim that the possibility of eradicating “faulty genes” is a mythical quest rather than a realistic goal. Wilson (2002) and Le Breton (2004) have argued that the “purity” promised by the Human Genome Project may not be possible. Earlier on, Ruth Hubbard and Elijah Wald (1993: 159) warned that it is impossible for the genome map to tell us “exactly where . . . every genetic inheritance of humankind is to be found.” They argued that a DNA molecule is an inert molecule, not a living thing, and thus contend that genes are not an
absolute predictor of disability. Just because a "pathological" gene may be marked, it does not necessarily follow that it will have a bearing on a future life. Moreover, cells and organisms can compensate for "genetic mistakes" (Hubbard and Wald, 1993: 11–12). Thus, cells or organisms might compensate for a "maladjusted" gene. Even if this "pathological" gene could be eliminated or altered by genetic therapy, it may begin a chain reaction that may result in disastrous consequences for the individual and society. It becomes a vicious cycle: the technological genetic intervention may solve one problem while creating another that then requires more technological intervention with its own unintended consequences (Baudrillard, 2000; Kroker, 2004; Hubbard, 1997; Le Breton, 2004).

**Populism, Liberalism, Individualism and Striving for Perfection**

Tom Shakespeare (1998: 665–68) argues that there is a continuum of impairment ranging from states such as being deaf, which may have mainly social consequences, to conditions like Tay-Sachs disease, which causes major suffering and leads to a very premature death. This must be taken into account when discussing the concept of choice in genetic intervention. But, at a certain level both the negation of a disabled presence through the changing of the faulty gene or the elimination of the foetus (the potentially disabled person) stem from a conflation of various components: the availability of technology, the populist notion of an idealized community and the validation of liberal individualism. This idealized view of community does not merely balance out liberalism and the constraints of group membership but transgresses both extremes (Bauman, 1988: 53). According to Bauman, this yearning is not simply a manifestation of nostalgia, but is embedded in privileged interpretations of present realities; these present realities privilege an able-bodied interpretation of what constitutes citizenship, in the sense of one who complies with normative standards that allow an individual to self-actualize and not be a burden to others.

Advocates arguing for both genetic testing for disabilities and the abortion of disabled foetuses claim that the quality for both the "afflicted" individuals and their families is diminished. They assert that the physical and social world require an able-bodied embodiment. The life of a disabled person is not worth living unless an intervention or accommodation raises their existence to an acceptable "quality of life." Of course, such an intervention or accommodation puts a strain on the limited resources a society has to offer. Moreover, as many feminists point out, caregivers of disabled people are mostly women. The care of disabled people does not give women the freedom to self-actualize, which is an important tenet of liberal individualism. Jenny Morris (1993) argues that such a viewpoint is ableist because it defines disabled people solely as a burden. Morris (1993) considers the provision of care as part of a reciprocal relationship between individuals...
which benefits both parties.

Some disabled people privilege their own versions of community and liberal individualism to justify genetic testing that discriminates against an able-bodied existence. Dirksen Bauman (2005), Trevor Johnson (2005) and Lennard Davis (1995) point out that some members of the Deaf community are advocating that deaf expectant parents undergo testing to determine if their unborn child can hear. If the child is presumed to be hearing, then an abortion would be encouraged because the birth of a hearing child within a deaf community would require accommodation that would not only upset the homeostasis of the community but also put an unnecessary strain on its resources (Davis, 1995: 163). Proponents of genetic testing for deafness argue that in a Deaf community, children’s quality of life is enhanced if they are Deaf. Similarly, the gene for a certain type of dwarfism has been isolated. Some people who experience dwarfism are undergoing this genetic test to ensure their children are dwarf. They argue that the strain of raising a non-dwarf child for dwarf parents who live in an environment that has been adapted to suit their stature is an unfair burden (Davis, 1995).

Both the “quality-of-life” and “self-actualization” arguments that underscore the “disability problem” are based on the sacrifice of the problematic minority (the prospective disabled child) in the name of the common good (an able-bodied and privileged society). In regard to the Deaf community and dwarf parents, the normative argument remains, although inverted. The minority (the prospective able-bodied child) is sacrificed in the name of the common good (for the good of the Deaf community and for the good of the dwarf familial unit). From a utilitarian sense, the eradication of prospective people that may be burdensome for others has an appeal (Hauerwas, 1995: 198).

Disabling of the Disabled

Today many members of society argue for genetic testing for disabilities because they believe that the “quality of life” for both the “afflicted” individuals and their “caregivers” is diminished. Will good parenting be measured by the extent of compliance to genetic technology? If so, what are the underlying pressures for women to submit their bodies to genetic testing, and genetic diagnostics? Judith Butler (1993: 7–8) makes some interesting observations about technology and the labelling of humans.

To claim that the subject is itself produced in and as a gendered matrix of relations is not to do away with the subject, but only to ask after the conditions of its emergence and operation .... In this sense, the matrix of gender relations is prior to the emergence of the “human.” Consider the medical interpellation that (the recent emergence of the sonogram notwithstanding) shifts an infant from an “it” to a “she” or a “he,” and in the naming, the girl is “girled,” brought into the domain of language and kinship through the interpellation of gender. But that “girling” of the girl does not end there; on the contrary, that founding interpellation
is reiterated by various authorities and throughout various intervals of
time to reinforce or contest this naturalised effect. The naming is at once
the setting of a boundary, and also the repeated inculcation of the norm.

I would argue the disabled subject is produced in an ableist matrix. One
must ask under what conditions does the disabled person emerge as
having a “bare life,” where his or her ability to achieve a “political life” is
in doubt? Or perhaps more correctly how does an ableist matrix prohibit a
disabled existence from coming to fruition? Just as Butler (1993) argues
that the matrix of gender relations is prior to the emergence of the
“human,” so too is the matrix of ableist abjection prior to the emergence of
the human. Just as the “girling” of the “girl” is achieved through the sono-
gram, the “disabling” of the “disabled” is achieved through a positive result
from genetic testing. From the perspective of gender, the “it” represented
by the sonogram has (if the mother chooses) the potential to be born, and
be a “person”—a “girled” person restrained by the hetero-normative
matrix that favours masculinity, but nevertheless having the ability to have
a “political life.”

The “it” represented by a positive outcome from the genetic testing
for disability becomes a signification of what can go “wrong” with a fragile
humanity. Thus, the “girling” of the “girl” (or the “boying” of the “boy”) is
overshadowed by the “marker” disability and its present and future impli-
cations. The interpellation of the “disabling” on the “it” does not result in
the expectation of a “political life,” instead, the “it” becomes the “abject”
other relegated to the “state of exception” requiring medical or rehabilitation
intervention to initially sustain its life, and then to “overcome” the effects
of its disability, if possible. The level of “political life” that the disabled
“state of exception” achieves is proportional to the extent that one “over-
comes” one’s disability.

By “naming” the infant “disabled,” he or she is abjectified. Making
the infant the “state of exception” to varying degrees paints the future not
only of the infant but also of the family and the community at large as a
series of problems and catastrophes that derive from the unfortunate cir-
cumstance of disability. Yet, as Elliot (2001) and Skidmore (1994) argue, it
is impossible to accurately predict the future “quality of life” of a disabled
person. If the disabled baby is born, then the marker “disability” looms
over the child’s life, or as Butler (1993) suggests, “the founding interpellation”
is reiterated by various authorities and throughout various intervals of
time to reinforce or contest this unnatural state. The naming of the disabled
demarcates or places them outside normality and, in doing so, repeatedly
reaffirms the norm. Thus, the binary of disability and non-disability serves
to reinforce normality within our society.

Jean Bethke Elshtain (1995: 35) claims that supporters of the primacy
of the “right to choice” for women have seemingly contradictory positions.
On one hand, they advocate genetic testing for disabilities, while on the
other they are appalled at any suggestion of testing for the sex of the foetus. Sophia Isako Wong (2002: 97) writes, "Feminists have spent ample time clarifying the distinction between biological sex (having chromosome XX or XY) and the social construction of gender." Moreover, Wong (2002: 97) asks, "Might there be an analogous distinction between trisomy 21 (having three twenty-first chromosomes instead of two) and the social construction of people with Down syndrome as disabled?" Wong (2002: 114–15) concludes:

I see no sharp line between the difficulties of being a woman in a patriarchal society and those engendered by having Down syndrome in a society focused on cognitive capacity. My intuition is that the possibilities for people with Down syndrome will increase as our society dismantles the deeply entrenched institutionalization of sexual difference. If we can move toward overcoming the Enlightenment fetishization of cognitive ability and dislodge the institutional barriers enforcing cognitive difference, perhaps we can build a society in which everyone is at home with Down syndrome.

As Wong argues, it is not simply a matter of women taking these contradictory positions in regards to genetic testing. Rather, women who are bestowed this right are being pressured into making the “correct” choice. The discourse concerning disability as it applies to the proliferation of reproductive technologies, in particular prenatal testing for detectable foetal anomalies, is not inclusive. Tremain (2006) Rapp and Ginsburg (2001), and Ettore (2001) agree that the offices of genetic counsellors, along with the overall environment, weigh the decision in favour of genetic testing. Rayna Rapp and Faye Ginsburg (2001: 538) assert, “[G]enetic counsellors are trained to express neutrality about the choice a pregnant woman and her partner may make around amniocentesis testing, the very essence of such technology and the offer of such tests under the terms of consumer choice are premised on the desire for normalcy and fear of unknown abnormalities.”

Following my segment on the radio program Cross Country Check Up, a mother of a disabled baby called the program. She explained how strangers would call her a “bad mother” for giving birth to a disabled child. Respondents to her segment accused her of being an irresponsible member of society for giving birth to a future “burden” on society. Like me, she was called irrational, especially after reiterating she loved her child. For the most part, respondents pathologized her decision-making abilities as well as her refusal to see the error of her ways.

The coercive nature of both public opinion and genetic counselling create an environment where the eradication of disability becomes “matter-of-fact” and “common sense,” and creates a guilt-free atmosphere where the initiative to get rid of a pathology is deemed necessary. The mother who chooses to carry the defective foetus to term (by either refusing genetic testing or ignoring a positive outcome) has her status of being worthy of a “political
life" questioned, especially if she does not acknowledge the error of her ways. Cautioning us about our reliance on the promise genomics, bioethicist Dr. Robert Klitzman (2006) warns, "As we enter the new genetic age, more education is needed to help doctors, nurses, genetics counselors, patients and their families face these quandaries. We have much to learn from the Greeks: to be cautious in interpreting prognostications, to beware that genetic information, like oracles, may offer an illusion of certainty."

From a feminist perspective, the "right of choice" is a founding principle. But competing ideologies can nullify this maxim. For example, a Deaf lesbian couple were unable to access sperm from a Deaf donor because of the screening process for disability (Bauman 2005). Developmentally disabled women are denied both an education about, and access to reproductive technologies (Dotson, Stinson and Christian, 2003). From a South Asian perspective, because of cultural norms and male dominance, women do not have the "the right to choose." Consequently, the Indian government has banned sonogram testing in an effort to stop the proliferation of abortions that are based upon sex selection (Moazam, 2004).

Thus far in my analysis I point to a "will to purity" (Critical Art Ensemble, 1998) that is deeply embedded in the fabric of liberal individualism and nostalgic populism. The continued dominance of genetic references in our everyday language gives the illusion that this "will to purity" makes "common sense" and is only "natural." There seems to be a historical need for particular characteristics of people to be the basis for being labeled a "state of exception." Gail Weiss (1999: 113) writes, "In a strange sense, there seems to be a natural progression in the category of the monstrous. Once we have ceased to be horrified and fascinated by alleged pathologies of the human, the impetus to create new monsters, new sites of horror and fascination seems almost inevitable." Genetic interventions could lead to new characteristics of abjection that would precipitate a greater narrowing of the normative range of what it means to have a "political life."

(Re)Affirming a Disabled "Bare Life" as an Expression of Life

Since 1997, I have become further embedded in the academic culture (a political life in Agamben's terms) and my life is further read as being greatly removed from my previous existence as a cripple, as a "bare life." It is assumed that I have evolved from my earlier existence as a baby who could not communicate, sit or control any aspect of either my body or my life (what many people believe is "a life not worth living" and the epitome of "the state of exception"). I feel tremendous pressure to put on a charade and try to present myself as human and subsume my spasms. Throughout my life I have had to work to maintain my status as living a political life. Moreover, I have had to take great care not to slip back to a "bare life" (or to be perceived by others to be slipping) and returning to the "state of exception."
I am restricted by what I call “normative shadows.” To varying degrees most people are restricted by “normative shadows”—a somewhat enigmatic and elusive concept—that lead to the suppression of desires that do not conform to accepted norms. Like most shadows, normative shadows cannot be grasped in a material way. They remain a feeling, a sense that one is constantly being judged according to differing criteria of normality. Like all shadows, normative shadows are elusive yet always present, simultaneously everywhere and nowhere. Yet, for those of us deemed as possible “states of exception,” adhering to “normative shadows” is a necessary precondition to maintaining a “political life.” A similar feeling is expressed by Neil Marcus who states, “People are always watching me... (ellipses in original) they’re watching to see how well I do this thing... (ellipses in original) this thing called ‘human”’ (Brueggemann, 2002: 322).

Following my appearance on Cross Canada Check-Up, many people congratulated me on my strong resistance to ableism. However, I question whether resistance could create a positive space for the vivaciousness of disabled existences. Addressing the question of resistance, Linda Martin Alcoff (1999: 67) writes, “There is a kind of quest purity in the attempt to maintain only a resistance which is itself defined as a reaction to power rather than a fight for power. Resistance so circumscribed suggests a desire to inhabit a space free from criticism, responsibility, and accountability, to be always a critic never the advocate.”

Simply put, I believe my disabled “expressions of life” should not defer to able-bodiedness. However, even resisting the privileging of able-bodiedness is a manner of “deference.” Always “reacting against” ableism rather than “fighting for” the affirmation of my spasms left me feeling empty. When articulating positions from the dichotomy of ability and disability, I feel restricted by the incessant need to respond to the normative shadows of able-embodiment that are omnipresent in discussions and influence the parameters for the “rules of engagement” as well as the means of articulation. In order to advocate, I agree with James Overboe (1999), who emphasizes a “singularity” that exists without the binary of ability and disability. My spasms are immanent desires that create a singularity that is neither “able” nor “disabled,” and affirms a disabled expression of life.

Earlier, I related that the radio program on genetics led me to examine my own genetic history. Similarly, reading Pure Immanence: Essays on a Life by Gilles Deleuze resulted in my finding a theoretical means to try and articulate my “expression of life” as a premature baby and its influence on me today. Gilles Deleuze (2005: 30) writes,

They connect with one another in a manner entirely different from how individuals connect. It even seems that a singular life might do without any individuality, without any other concomitant that individualises it. For example, very small children all resemble one another and have hardly any individuality, but they have singularities: a smile, a gesture, a
funny face—not subjective qualities. Small children, through all their sufferings and weakness, are infused with an immanent life that is pure and even bliss.

Rosi Braidotti (2005–2006) calls for an “ethics of immanence” that eschews biological determinism and instead values “the co-presence of different elements, from different stages of evolution, like inhabiting different time-zones simultaneously.” Often, I give myself a respite from my charade of having to lead a “political life” by traversing time zones and emphasizing elements associated with my living the “bare life” as a premature baby experiencing cerebral palsy.

More and more, my life feels the expressions of life that are not restricted to the notion of self that is territorialized by the concomitant of able-bodiedness that individualizes me. This individualism stifles these expressions of life that have been superficially labelled as “spasms” and “cerebral palsy” (negative interpellations imposed upon me) that fail to capture their vivacity. Deleuze makes a distinction between living an empiricist life, as compared to what John Locke called the “self.” John Rajchman (2005: 8) explains that a life differs from the self, which is characterized by self-consciousness, memory, and personal identity. It unfolds according to “impersonal individuation rather than personal individuation, of singularities rather than particularities. It can never be completely specified. It is always indefinite—a life.” Quite often, I step back from the strains of the “will to purity” and its cherished manifestations, the (sterilized) communities and the (self-actualized) self, and breathe a life—indefinite—and singularities that allow for my “expressions of life” that have been shackled by a (restrictive) humanism to be affirmed.

In the following passages from the article “Miracle Kid” by Lucinda Franks, a family with a child with Fraser syndrome relate how they risk going against both normative assumptions and expert advice in order to affirm the (bare) life of their son, Max, who is living as a “state of exception.”

“I don’t know what this is, I just don’t know,” a doctor said as he put the baby into her [Max’s mother’s] arms. Beneath the lush head of hair, the baby’s face was like a child’s unfinished drawing. He had only one, unnaturally small eye, on the right side of his face. On the other side, there was a concave blankness beneath the brow. His nostrils were separated by a deep cleft, and his nasal ridge was squashed. Penelope took his curled fist and felt for fingers, but none were there [later Bernard discovered Max had fingers and toes] (Franks, 1999: 68).

Penelope and Bernard had to overcome the medical staff’s negative attitude towards Max. As Penelope kept watch over Max, she noticed clusters of interns and residents came to look, and heard some of them referring to him as “it.” Finally, Penelope had enough. “This ‘it’ is my son, and he wants to be left alone,” she said. Penelope persuaded a reluctant nurse to
put the child to her breast, and he began to suck vigorously. The nurse said firmly, “It’s only instinct. Any baby will nurse (original emphasis).” Then she pointed out another nurse who was unhooking a plump baby from a ventilator and rushing out the door with him, “That baby has been on life support for months,” the first nurse said, “It has been unending agony for the mother, and she’s decided to end it. She’s waiting in a private room so the baby can die in her arms” (Franks, 1999: 69). In comparing Max to the other baby, the nurse was placing Max in the realm of the “state of exception”—a “bare life” that was “not worth living.”

This interpellation of the “bare life” that is the “state of exception” was reinforced by other medical practitioners outside the hospital. Max required various health professionals for his ongoing home-care. “The original day nurse was fired after Lulu, the babysitter, caught her washing Max’s bottles in dirty dishwater. ‘What’s the difference? He is going to be a vegetable,’ the nurse said with a shrug” (Franks, 1999: 69).

The predominant attitude towards Max epitomizes the belief that some disabled infants’ existence is “not worth living.” Franks (1999: 71) reports,

At a meeting to discuss Max’s future, with the support of out-dated information a hospital official advised, Max’s parents might be better off warehousing him for his sake and theirs. Armed with positive research on Fraser Syndrome, Penelope jumped in. “We do not intend to warehouse our son,” she said icily, “There’s only one option we’d like to discuss, and that is aggressive medical intervention.”

Franks (1999: 77) asserts,

Max has had a profound positive effect on his mother: “The truth is that Max has made me more deeply happy than I have ever been,” she explained. “He changes everyone who meets him. He changes their ideas about beauty, about worth. He has made every member of our family—immediate as well as extended—grow up and change their life view in some essential way.” Max also changed the attitude of many members of the hospital staff. “We think everyone has to be perfect, physically, mentally,” Dr. Flaum said, “It’s easy to write people off, say, this one’s so abnormal forget it. Max has reaffirmed that you cannot look at a person and know for sure he has no ability to learn and be a good member of our society.”

Shannon Sullivan (1997: 13) argues that when our own embodiment and our subjectivity become the standard for our interpretation of others, the notion of inter-subjectivity is problematic in that “I encounter only myself and my own meaning.” The problem with inter-subjectivity is that non-disabled caregivers cannot see themselves in the “bare lives” that are the “state of exception” (in this case Max) or perceive any meaning in their existence. The breakdown with inter-subjectivity occurs because of a phenomenology which privileges a non-disabled aesthetic and cannot perceive
its embodiment or aesthetic reflected by a disabled “expression of life” unless it is subsumed by a “normative facsimile,” as represented by people who, to varying degrees, “overcome” their disabilities and evolve into people having a “political life.” Unless this subsumable process takes place, many people consider the lives of these disabled people as lacking any meaningful existence. The article by Franks ends with Max talking with another boy about toy fire trucks, thus illustrating Max’s (potential) worthiness to be included into the community of “political life.”

In his analysis of Pure Immanence: Essays on a Life, Agamben (1999: 135) believes that for Deleuze, “the term life designates nothing more and nothing less than the immanence of desire in itself” [emphasis in original]. The desire from my “bare life,” my spasms, created an immanence of life that is pure (without the will). Perhaps the “pure immanence of life” associated with Max’s experience of Fraser Syndrome created an expression of life that has, thus far, remained unacknowledged. Echoing Braidotti, perhaps Max’s expressions of life will traverse time zones and his experience of “pure immanence” as a baby with Fraser Syndrome will be acknowledged.

Due to our respective disabilities, both Max and I were perceived to have a negative ontology (Titchkosky, 2005: 663). Deleuze believes in the concept of ontology; however, he would disagree with the limitations imposed by a negative ontology. From the perspective of ontology, Todd May (2005: 15) writes, “To read Deleuze is to be introduced into a world of proliferating beings and new life forms.” Thus, Deleuze is always open to new forms of ontology which affirm different expressions of life. The affirmative expressions of life of both Max and I resulted from our respective ontological senses that eschew the limitations of the binary of disability and non-disability. “Deleuze drives the [traditional philosophical] project [of ontology] to its limit, a limit in which he finds the question of how one might live to be raised afresh and ready to offer surprising answers” (May 2005: 15–16). Through our “expression of life” both Max and I drive ontology to the limit, offering “surprising answers.”

In conclusion, the genie (genetic research) cannot be resealed into the bottle. Public opinion will decide if, and to what extent, genetic testing and genetic interventions will be utilized. Presently, the “promise” of, and search for the Holy Grail (Human Genomics), has given rise to genetic fundamentalism as the predominant view within public discourse. This paper affirms that a disabled “bare life” can be added to the dissenting voices that are critical of the proponents of genetic fundamentalism. Once the voices of dissent reach a critical mass, perhaps members of various societies can engage in a meaningful discussion about the meaning of diversity. And as the dialogues continue, ask the question: Is it time to move beyond (restrictive) notions of humanism and instead affirm and embrace other “expressions of life,” including “bare lives” that thus far have been “states of exceptions?”
References


