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Is There a Gene Responsible For Our Obsession With Perfection?

Disability, Ethics and Responsibility

My mother gave birth to me. A small baby like me.
Sing song, put in the cot, cradle as well Small clothes, small face, small body. Old photos
about me
Born here, Down Syndrome My father Down Syndrome My mother Down Syndrome I'm
perfect.
Perfect Baby. Perfect Child.
Perfect Woman (Rita Halabarec)

Creative works such as those performed by Geelong's Back to Back Theatre demonstrate how the term disability is being reconstructed, transformed and subverted. Performing artists are actively challenging negative representations of disability by making visible a body seen to have existed largely through the gaze of medical abjection. At the same time, however, prenatal screening, and genetic engineering more broadly, holds out promise for a world where traits like Down syndrome cease to exist. This poem, written by a performer who played in Back to Back Theatre's 2002 Melbourne Festival production of *Soft*, offers a challenge to discourses that perpetuate the belief that disability equals imperfection, disadvantage and suffering. *Soft* grapples with the highly controversial ethical issues of prenatal screening and the pursuit of perfection by asking the question – 'Is there a gene responsible for our obsession with perfection?'

As the work was devised out of conversations with scientists working in the area of genetics, the performers were well aware that conditions such as Down syndrome are targeted for termination. Some of the performers in *Soft* possess the characteristics in question.. The 'real' life context through which '*Soft* was conceived provides an insight and intelligibility capable of responding to such discursive practices. In this regard the performance plays an important ethical and political function. *Soft* encourages us to contemplate the contemporary treatment of disability in our society, but also the implications for humanity as a whole. The production provokes broader questions about embodiment and the human condition that demand an engagement with 'Otherness', ethics and responsibility. It also raises deeply complex and difficult issues relating to agency and the balance between the

theatre aesthetic, entertainment and the political message. This essay explores the theatrical and spatial features of *Soft*, and the ways in which it facilitates a vastly different reading from those encountered in both the reviews and disability rights critiques of prenatal screening. It does so by situating these debates in the context of Emmanuel Levinas's work on ethical relations.

One of the criticisms often targeted at companies that include people with disabilities is the extent to which able-bodied directors control the artistic product. Most of the company's work, as Director Bruce Gladwin remarks, does not necessarily make a direct comment on disability, 'but [in] this show [it] seemed really pertinent to actually explore it for once' (Gladwin, 2002). According to Gladwin, the work evolved over many years but the story was ultimately derived from 'what the performers had to offer from their engagement with the research material' (Gladwin, 2002). In *Soft*, as in many Back to Back Theatre productions, able-bodied and disabled actors work collaboratively, encompassing the important insight that disabled and non-disabled are constructed in mutual relation. Back to Back acknowledge that their company is read as a disabled company, but they are careful to insist that it is only a perception, and one that the performers themselves do not embody. Back to Back is an ensemble of five actors who, as promotional material and their web site suggests, are 'professional actors considered to have an intellectual disability' (Back to Back). The term 'considered' here indicates the power relations involved in constructing the category of intellectual disability, but also indicates to an audience that the performers themselves do not identify with this category. One of the performers, Sonia Teuben, states, 'I don't see our disability as important. I see us as human; disability is just a word like coffee, tea, cigarettes, not actually a disease' (Teuben, 2002). [1]

The actual performance is layered in a way that skillfully avoids didactic forms of self-representation or blatant political overtones. As Gladwin explains:

This play is really trying to analyse what it means to be human in the year 2002 and not what it was like to be human when Shakespeare wrote his plays, and I feel like it's a quest for new stories and new narratives, and I think that what is happening to people with disabilities in regard to genetic technology is really pertinent for the rest of us as a community. (...) Rather than making a show that's thematically about how difficult it is for people with disabilities in our community - we go, we'll make a sublime piece of art and people see that, and the advocacy works on a number of levels. We made a play about prenatal screening but the fact that as soon as the play starts there's three actors that walk on with that genetic condition - that's a fairly strong form of advocacy and we don't have to even open our mouths (Gladwin, 2002).

The theatrical spatial arrangement in *Soft* significantly disrupts the typical separation between audience and performer. 'The first factor that strikes us when we enter a theatre', suggests Keir Elam, 'is the physical organisation of the playhouse itself: its dimensions, the stage-audience distance, the structure of the auditorium (and thus the spectator's own

position in relation to his fellows and to the performers) and the size and form of the awaiting stage' (Elam, 2002: 50). *Soft* offers a challenge to many of the traditional theatrical codes that concern these proxemic relations because the performance takes place, not in a traditional playhouse or theatre, where stage and audience are clearly separated, but in an unused shed in the Melbourne Docklands. The performance space houses, at least for the first half of the performance, a giant, purpose-built inflatable bubble where performers and audience are brought together. While the audience has a sense of being together in a shared space with the performers, an intense feeling of isolation is created with each audience member required to wear headphones. We see and hear from the inside out, as if we, the audience, are not yet formed, not yet human. The space in which the audience is seated is womb-like in structure. The walls come alive, through the use of sophisticated multimedia technologies, with colourful imagery of mutating cells, genes, sperm and energy. Its delicate, tissue-like enclosure is the active surface on which lighting and digitally enhanced imagery is projected. This space invites a sensibility, following Elam, that 'does not coincide with its actual physical limits' (Elam, 2002: 60).

Soft consists of two separate but interrelated narratives. In the first section, the primary characters are a couple, Martin and Marianne. The story is set in a contemporary context, in which the theme of embodied perfection is explored via a number of different cultural practices — a dog show; a couple's purchase of the optimum motor vehicle; the tender and angst-ridden contemplations of the same couple, Martin and Marianne, over whether or not to abort a foetus with Down syndrome, all the while attended by medical practitioners who themselves embody (both actors and characters) the same genetic condition. The first half of the performance culminates in Martin and Marianne deciding to terminate their pregnancy after they have been told by the genetic counsellor that the child has a genetic make-up that will lead to Down syndrome. Before the commencement of the second half of the performance, the inflatable bubble is struck loudly and sucked out from the back of the performance space to reveal the stark void that transforms the set for the rest of the performance. This futuristic space is bare but for the scattering of a few giant Stem Cells (resembling the same inflatable, tissue-like substance of the initial performance space). The narrative primarily focuses on the relationship between a genetic Investigator and Man X (as he is referred to in the script), whose identity and existence is called into question by DNA tests unable to account for the existence of his chromosomal anomaly. He is eventually identified as the last person on earth to have an extra chromosome — 'the last of the Mohicans', says the Investigator's assistant (Back to Back, 2002). Here the audience is propelled into the future as a jolting reminder that our society has continued to operate according to the logic of decisions made about who deserves to be born. It also acts as a summons for the audience to respond and be responsible.

Rather than reinforcing an able/disabled binary by referring to their own condition, the performers of *Soft* ask, 'is there a gene responsible for our obsession with perfection?' This question immediately and ironically places the quest for perfection as itself a defective gene belonging to those who pursue it. Nevertheless, the visible presence of the disabled body does not guarantee ethical spectatorship. When disabled people perform, as Petra Kupperts notes, 'they are often not primarily seen as performers, but as "disabled" people'

(Kuppers, 2003: 49-50). In this instance the visible presence of the disabled body necessarily turns the audience into spectators where the relation to the Other is perceived from the point of recognition and knowledge.



Marcia Ferguson, Darren Riches, Mark Deans, Nicki Holland, Sonia Teuben, Rita Halabarec, Jim Russell, *Soft*, Back to Back Theatre. Photographer Jeff Busby

As Levinas states, ‘inasmuch as the access to beings concerns vision, it dominates those beings, exercises a power over them’ (Levinas, 1991a: 194). The Other, for Levinas, always exceeds and transcends the image I make of the other person. This is where Levinas is sceptical of any art form that relies on the visual image because experience often remains within the realms of intelligibility. ‘The relation with the Other alone’, he states, ‘introduces a dimension of transcendence, and leads us to a relation totally different from experience in the sensible sense of the term, relative and egoist’ (ibid, 1991a: 193). Levinas speaks of a different sensibility, one not ‘graspable by introspection’ because this is ‘already a perception’, he argues (ibid, 1991a: 187). Sensibility does not belong to the order of the visible or being but is before essence and before identity. Sensibility, writes Levinas, ‘is exposedness to the other’ (Levinas, 1991b: 75). This takes place, he argues, in the face-to-face relation. However, the face, while retaining a corporeal presence, also exceeds or goes beyond phenomenality. The face is not to be taken as merely visage. ‘The whole body— a hand’, says Levinas, ‘or a curve of the shoulder— can express as the face’ (Levinas, 1991a: 262). Reading *Soft* through the work of Levinas offers not only the possibility for an alternative ethics and sensibility on disability but a different way of thinking about the relations between ‘Self’ and ‘Other’.

Levinas's work on the ethics of the face proves useful, as 'facing' another is central to exploring the actor/audience dynamic. His understanding of the face of the Other paves the way for a richer form of enquiry than that merely concerned with elucidating the theatrical expression of particular disabled ontologies. The performance, I argue, resists the representation of a disabled ontology and facilitates a relationship with alterity that transcends the visible disabled body. By manoeuvring the audience into a position that allows it to be challenged and contested, the work instigates, I argue, the ethical relation Levinas refers to as Substitution – putting oneself in the place of another.

This is achieved in two innovative ways. The first is through the womb-like structure of the performance space itself, where the audience members collectively occupy the position of the unborn foetus. In this way we are obliged to put aside any definitive thoughts about the Other and are left without the opportunity to contemplate the Other purely from our own experiences. Substituting oneself for another takes place because 'the other is in me and in the midst of my very identification' (Levinas, 1991b: 125). The second example is the face-to-face relationship with the Other in the second part of the play. Do we acknowledge the humanity of the Other or fail to, resulting in the other person becoming a faceless face 'whose life or death is for me a matter of indifference' (Critchley, 2002: 13)? The relationship between the Investigator and Man X serves as a useful guide through which to reflect on such questions. This is a relationship that enacts an ethical responsibility toward the Other and provides the spectator with a framework for considering the ethics involved. The shift in focus from the disabled body to questions of the 'gene responsible for the obsession with perfection' opens the debate to explore socially constructed notions of disability. I turn to these debates in the section to follow.

Many of the ethical debates in circulation inevitably start from the acknowledgement of particular disabled ontologies. These debates become particularly complex in light of Levinas's insistence that adherence to ontology prevents us from engaging responsibly with human injustices. According to Levinas, any relation to Otherness that is reducible to comprehension or understanding goes by the general term ontology (Critchley, 2002: 11). The subject matter of *Soft* directly impacts on the lives of people caught up in the discursive practices of prenatal testing. These are not merely fictitious representations but real lives whose existence is actually (on stage and off) called into question. Rebecca Cook, for instance, writes:

Soft investigates the increasingly blurry line between humanity and technology with a poignancy that is beyond description here – but try thinking about how a person with Down syndrome feels when they hear about scientists working to eradicate people like them from future existence and you might get some idea. (Cook, 2002: 63)

Similarly, Helen Thomson remarks, 'they ask us to consider what the world would be like if people like themselves – intellectually disabled – no longer existed' (Thomson, 2002: 5). In these interpretations, the story is understood as one in which people with Down syndrome (or intellectually disabled, as Thomson asserts) are trying to reconcile the fact

that their embodied being is marked unworthy of reproduction. 'How must that feel?,' we are asked.

Turning to the scenes in *Soft* where Martin and Marianne attend the hospital to receive the results of an amniocentesis best reveal the relation Cook and Thomson describe. [2] The doctor informs them that their child will have Down syndrome, then turns to ask what they know of this genetic condition. 'I've seen people with it', says Marianne. 'I saw a TV documentary about people who had it', replies Martin. The genetic counsellor offers to gather more information. 'While you're waiting', she says, 'feel free to talk to Doctor Holland, because Doctor Holland actually has Down syndrome'. Marianne responds to Doctor Holland with: 'I wondered, I thought yeah, I didn't want to ask, but I thought that you did'. Marianne then asks whether the nurse has it too. The following dialogue ensues:

Doctor: I'll ask her. Do you have Down syndrome?

Nurse: Me?

Doctor: Yeah, do you have DS?

Nurse: Yes

Doctor: Yeah, she's got it

Martin: How do you cope with it?

Doctor: I can do whatever I want to do. Do operations. I can sing, I can dance.

(Doctor breaks into song)

'Isn't it rich, aren't we a pair?

Me here at last on the ground, you in mid air!

Send in the clowns!'

Doctor: You know the rest.

A little later Martin checks with the doctor and counsellor to make sure it's not too late if they decide to terminate. The Doctor's reply and subsequent behaviour show that she is insulted: 'Shit. Fucking hell.' (Storms off). The nurse does likewise. The counsellor subsequently turns to Martin and Marianne and says, 'you have to understand that for Doctor Holland the idea of terminating a pregnancy with Down syndrome questions her own existence within our community. She gets very upset'. Doctor Holland continues to sob and swear under her breath and is comforted by the counsellor. When Martin and Marianne return to the hospital, after making their decision to terminate, the input from both the doctor and the nurse is neither non-directive nor neutral:

Marianne: We want a termination.

Doctor: Shit. Have you thought about this?

Martin: Yes.

Doctor: Take a couple more days.

Martin: No.

Doctor: Shit. Bloody Fuck.

Nurse: It's not funny mate

Counsellor: Doctor Holland, this is supposed to be a non-directive counselling process.

Doctor: What's that?

Counsellor: You have to let the client make their own decision. Doctor: Yeah, I know that.

Counsellor: (to the couple) It's been a very difficult decision. Martin: We feel we are doing the right thing for the child.

Counsellor: Yes.

Counsellor exits

Doctor: Nurse, get the surgery ready. Come on let's go. It's fine. Whatever you want.

This segment of the performance highlights two of the central arguments that disability scholars pursue. The first is that notions of 'choice' need to be contextualised within a broader political, social and ethical context rather than remain in the personal realm. If decisions about terminating a pregnancy are made in a societal context that perpetuates the idea that parenting a child with a disability promises grief and suffering to the child, then 'choice' is a misnomer. What qualifies as a disabling trait is the subject of what Adrienne Asch and others refer to as 'line-drawing.' [3] That is, the idea that parents should be warned about the risks of giving birth to certain characteristics considered disabling and difficult, including Down syndrome, cystic fibrosis and muscular dystrophy (Asch, 2003: 339). Asch argues that at present the education of clinicians and counsellors provides little opportunity for actual contact with disabled children or adults outside medical settings, and that this too often hampers reproductive choice. An especially troubling example of this situation, for Asch, is the contradictory information given to parents and families by clinicians. Drawing on the research findings of Lippman and Wilfond, she writes:

In situations where parents were raising infants and young children with Down syndrome and cystic fibrosis, counsellors stressed ways in which lives of the affected children would resemble those of non-disabled peers, focusing on capacities for education, stimulation, play, and relationships. By contrast, the stories given to prospective parents if the diagnosis was made prenatally concentrated on medical complications and differences from the lives of non-disabled children. (Asch, 2003: 334)

Such differences in information, argues Asch, 'run afoul of non-directiveness' (Asch, 2003: 334). The second argument concerns the absence of the voices of people with a disability, and how this leads to mistaken assumptions about disability and quality of life issues. The right to abortion is not in question but rather, as Ruth Hubbard puts it, 'decisions about what kind of baby to bear inevitably are bedevilled by overt and unspoken judgments about which lives are 'worth living'' (Hubbard, 1997: 199). Disability, many insist, continues to be perceived as a medical problem and thus its elimination is seen to be beneficial. Bill

Albert, chair of the International Sub-Committee of the British Council of Disabled People, expresses this succinctly:

Genetic research and its clinical applications are creating an ethical minefield. Disabled people offer a unique perspective on the issues and one which may help everyone chart a safer route. This is because we know the real territory which genetics assumes as its own – the quality of our lives. And in this territory we are the 'native guides' although, unlike indigenous guides before us, we have been largely ignored by the new explorers, except as objects for elimination. But we do not want to be eliminated by contemporary colonisers, the geneticists. Neither do we want people who might be like us to be eliminated. Our lives have a value equal to that of able bodied people. (Albert, 1999: 1)

Albert is not alone in speaking of a collective 'we' of disabled people for whom the issues that genetic research present have direct implications for a disabled ontology and identity. As disability scholar Jenny Morris maintains:

people whose bodies look and behave differently do not 'belong' and our experiences are feared by non-disabled people who do not like to be reminded of the vulnerability of the human body. (...) Exclusion is indicative of our experience of an unequal power relationship: other people make decisions about our lives and in this case about our very right to exist. Such an exclusion must not persist for we have a right to be involved in the discussions and decision-making which so fundamentally affects our lives. (Morris, 1992: 16-17)

Several disability scholars have drawn parallels between Nazi eugenic practices and contemporary practices, in which scientists and physicians make decisions about who deserves to live or be born. [4] While Nazi and contemporary practices differ, says Hubbard, 'a similar eugenic ideology underlies what happened then and the techniques now being developed' (Hubbard, 1997: 195). The study of genetics, as Michelle La Fontaine argues, 'has created the notion that perfection is indeed possible using logical positivist methods' (La Fontaine, 2003: 45). People who are socially constructed as disabled, continues La Fontaine, 'are a primary target of this schema, particularly those who have conditions of a genetic origin' (2003: 45). *Interaction* devoted a special issue in 2000 to an exploration of bioethical issues for people with disability, 'most of the contributors being people with disability' (Newell, 2000: 4). Gerard Goggin and Christopher Newell explore these issues in an Australian context in *Disability in Australia: Exposing a Social Apartheid*. According to Goggin and Newell, our culture is dominated by the myth of what they call the 'catastrophe of disability'. 'Underlying the narrative structure of the disability-as-catastrophe story', they suggest, 'are two profoundly contentious assumptions now well critiqued by disability activists and scholars':

Firstly, that disability is an individualised experience as opposed to being created and perpetuated by society, and, as a corollary, that people with disabilities are not actors but are to be acted upon. Secondly, and paradoxically, that technology is at one and the same time value neutral and yet also inherently good for people with disabilities. (Goggin and Newell, 2005: 107)

These debates, and the specific voices of those implicated, provide a powerful reminder that disability exists in a social context that undervalues difference and overvalues 'ableism' and notions of independence. It might seem that here the humanity denied in much discourse on disability is installed and an ethical response enacted. However, the arguments are polarised. On one side the geneticists exclude the voices of disabled people and justify the eradication of disability on the grounds that it is a form of suffering. This perpetuates unequal power relations. On the other side, people with disabilities suffer from the injustice inflicted on them by exclusionary discourses. Both perspectives provide little opportunity to move beyond an abled/disabled binary. Ethics, from a disability studies critique of prenatal screening and genetic engineering, relies on the ontological given of the disabled body. This kind of ethics is also implied in the reviews of *Soft* already discussed. To read the performance in the ways Cook and Thomson do, for instance, is to remove oneself from the performance space, thereby failing to face the Other. Moreover, the distinctions between actor and character are collapsed and the performance is perceived through a gaze that is 'not about me'. This is just the kind of gaze Levinas opposes. The problems, as I understand them, are: actors are reduced to a disabled identity and consequently to a position of vulnerability, where a clear separation is established between 'us' (audience/able bodied) and 'them' (actor/character/people with disabilities). There is clearly an 'us' and 'them', 'self and 'other', and a construction of oneself and a distancing of 'the Other'. This reading, I argue, serves to thwart the possibility of an ethical response in the Levinasian sense.

For Levinas, the ethical relation means moving beyond ontology where the 'Other' cannot simply be reduced to the 'Same'; moving, that is, to comprehension or understanding. 'To remain the same', states Levinas, 'is to represent to oneself' (Levinas, 1991a: 126). As Critchley argues, 'if the other person were reducible to the concept I have of him or her, then that would make the relation to the other a relation of knowledge or an epistemological feature' (Critchley, 2002: 11). Relating to the Other, then, as in the naming of 'intellectually disabled' or 'a person with Down syndrome', is to reduce the Other to one's own perceptions. As Levinas writes, 'the word that bears on the Other as a theme seems to contain the Other' (Levinas, 1991a: 195). The interplay between the written text, the performance text and the spatial features of the performance facilitates a rethinking of the self/other relation. If the performance is construed as one that asks us to consider a world without people with disabilities, the Other 'is reduced to the Same through the process of designation (identity)' (Sullivan, 2001: 104). Reducing the Other to the Same is to perform an act of partial negation. 'A partial negation, which is violence', contends Levinas:

And this partialness can be described by the fact that, without disappearing, beings are in my power. The partial negation which is violence denies the independence of beings: they are mine. Possession is the mode by which a being, while existing, is partially denied. (Levinas, 1998: 9)

This act of negation and appropriation cannot materialise when we are situated inside the womb. That is, when we are not mere spectators, but where the Other is within the Same. In the scenes I described earlier, we are the foetus, not yet born, not yet human, but waiting, in absolute vulnerability and ontological uncertainty, the outcome that is both our individual and collective fate. The situation here is not one where I consider a world without ‘people like them’, but rather where I put myself in the place of another – bound to the Other in the state of maternity. In this way, Levinas’s ethical relation is set in motion and realised. The metaphorical womb acts not in order for us to ponder the Other’s vulnerability from our own principles but as a summons to inhabit the vulnerability that arises from the ‘becoming’ that is gestation. The act of being imagined into the womb can be associated with what Levinas refers to as Substitution. This is the relation where we put ourselves in the place of the other – the Other is within the Same, rather than, as Peter Atterton and Matthew Calarco put it, ‘the Other as an other Same’ (Atterton and Calarco, 2005: 65). To borrow Shildrick’s phrase, ‘I do not put *myself* in the place of the other, so much as I am occupied by it’ (Shildrick, 2002: 93; original emphasis). Substitution is a relation with the Other that ‘introduces into me what was not in me’ (Levinas, 1991a: 203). The second section of the play where Man X is interrogated highlights, in a different way, the condition of the ethical relation, made possible not only by the bond that develops between the two individuals but in the inability to identify the Other. ‘The face is present in its refusal to be contained’ (Levinas, 1991a: 194). As a consequence, the Investigator’s subject position is called into question by the Other in a way that compels him to act responsibly. It takes us into a realm of relations where it is the enigma of the Other in the face-to-face relation, rather than a knowingness that calls us to respond.

Man X has been marshalled into a room by a giant stem cell. He is subjected to a series of degrading and humiliating tests and observations, justified on the suspicion that he might not be human. Man X is constructed as ‘Other’ and less than human. He deliberately evades the questions posed to him by his interrogator about his identity. Over time the Investigator’s identity is called into question but not before we witness his struggle to preserve integrity and superiority. For example, in one scene Man X is being observed in his cell through one-way glass. What the Investigator sees is Man X mimicking the Investigator’s behaviour. The Investigator is so angered that he provokes a fight with Man X. Amidst the scuffle Man X exclaims that the Investigator is ‘a sick man’. The Investigator verbally retaliates by saying, ‘you’re a fucking weirdo’, to which Man X replies, ‘you are’. The Investigator is visibly shaken by the whole experience but is assured of his worthiness as a decent and good human being by his assistant. A little later the Investigator undertakes another interrogation, this time designed to test for emotional response. He poses several questions and presents Man X with a form to write down his response but each time Man X remains silent and hands the form back to the Investigator. After the Investigator asks the following questions, however, the relationship takes an unexpected turn:

You live alone, you feel isolated within the community and question your ability to contribute. You are overwhelmed by a sense of failure. What do you do? Do you punch the guy next door when he starts his lawn mower at 8.00am every Saturday morning? Do you abuse the cleaner when she eats the tuna in the fridge? Do you continue working as a glorified lab assistant even though your parents selected your genetic makeup to be a brain surgeon? (Back to Back, 2002)

Before Man X has time to respond the Investigator glazes over and appears introverted, as if the questions reach the depths of his existence and rouse him to reflect on his own failures. While the Investigator points to himself, he announces, 'I was born to succeed. There are 20 special people in the world and I'm not one of them. I'm not happy. I'm not happy'. Man X beckons him over but the Investigator is afraid he'll be hurt. 'I'm not going to hurt you', says Man X, who then takes him by the hand, strokes the Investigator's face and embraces him. This time, when Man X tells him he is sick, the Investigator acknowledges, 'Yes, I'm a sick man'. The ethical relation is operative here - the Other calls the Investigator's subject position into question. Put another way, drawing on Shildrick's eloquent phrasing:

Although initially it is the other who is vulnerable, who is figured as homeless, poor, widowed, orphaned, and whose suffering humanity invokes response, that response itself – or rather the irresistibility of the call – pitches me also into vulnerability. *I* am exposed before the nakedness of the face, the certainty of my own existence thrown into doubt. (Shildrick, 2002: 92; original emphasis)

The next day the Investigator arrives at work with a rejuvenated energy and heads straight to the cell where Man X is being held, despite being told that he is to return to normal duties and is not to approach the cell. The Investigator enters and immediately tears up the emotional response form. At this point, the Investigator clearly begins to take responsibility – to acknowledge and sense the Other. The Other, as Alphonso Lingis states, 'is not experienced as an empty pure place and means for the world to exhibit another perspective, but as a contestation of my appropriation of the world, as a disturbance in the play of the world, a break in its cohesion' (Lingis, 1991: xxiii). The presentation of the face, writes Levinas, 'does not disclose an inward world previously closed, adding thus a new region to comprehend or to take over. On the contrary, it calls to me above and beyond the given that speech already puts in common among us' (Levinas, 1991a: 212). This call is evident in the Investigator's behaviour. For instance, he shows Man X where he lives, asks him if he is hungry, if he is OK and then, with a sense of urgency, states, 'We have to get out of here, it's not good for you to be here'. Man X then pulls a wallet out of his pocket and shows an identification card with his name (Colin Malop) and address.

On attempting to leave the building, security send in giant Stem Cells to obstruct their exit. The Investigator pleads with the Stem Cells by proclaiming, 'this man means no harm. He's a good man. Colin is a human just like me, just like you. Colin's future, our future, now

lies in your hands. Please let us move forward' (Back to Back, 2002). In these final moments Colin comes forward and subdues the stem cell with gentle caresses. Once out of the building, the Investigator asks Colin if he'd fancy having a beer with him. Instead, Colin leads the Investigator to his house. They climb the stairs and Colin stands looking out his window, directly facing the audience. The Investigator asks, 'What are you looking at Colin?' – 'People', he replies. 'Colin?', says the Investigator, in a tone that suggests he doesn't quite understand. The play concludes with Colin saying 'Goodnight'. In this final scene, we, the audience are again witness to the subject positions that make ethics possible – that of responsibility. The Investigator's subjective experience is one structured through a relationship of responsibility, called forth by the Other. Responsibility is a term Lingis describes as a bond with an imperative order, a command (Lingis, 1991: xiii). A Levinasian ethics serves as an invaluable theoretical tool for provoking the subject to act responsibly toward the Other.

In *Soft* the audience is confronted with the representation of bodies that are, to use Margrit Shildrick's words, embedded in 'material situations in which power and other differentials are already established and have a history' (Shildrick, 2002: 100). I have considered the benefits of performance strategies that facilitate the destabilisation of ontological thinking. *Soft* provides representations of social interactions that subvert and confront our preconception of disabled people as the defective 'Other'. A strong argument could be made for reading this performance as an instrument of social change, addressing and indeed inverting, many of the concerns expressed by disability scholars. For those who have never had the opportunity to be acquainted with people with disabilities, the actors in *Soft* are a vivid reminder, to borrow from Asch, 'that realms of activity often thought unimaginable for people with disabilities are components of many of their lives' (Asch, 2003: 324). Taken as evidence of embodied difference, narratives from the performers in *Soft* also serve to challenge and contradict what Philipa Rothfield calls, 'the *disembodied universalism* that is so often invoked in ethical discussions' (Rothfield, 1995: 169; original emphasis). The particular scenes I have drawn attention to have hopefully contributed in ways that 'impact on our approach to concrete situations so that we come to see them as ethical' (Bernasconi, 2002: 250).

There is no doubt that disabled bodies unavoidably fall short of the standards set in light of the new technologies, of which the mapping of the human genome is one. If Levinas's thesis is adopted, an ethical response becomes possible by resisting reducing the Other to the Same (Critchley, 2002: 17). In this way, we are not only affected by the Other but our own Sameness is called into question. Applying these principles to subjects already constructed through 'Othering' discourses serves as a timely reminder to rethink the taken-for-granted ontological categories that the term disabled imposes. Levinas's caution about ontology responds to the vast differences that already make thinking about the category disability in terms of abjection, unethical.

The play's engagement with the issue of prenatal testing offers a unique perspective in this regard. *Soft* poses significant contestations to dominant medical discourses at the same time as it generates a responsibility toward the Other. If one is able to approach the Other

without resolving them into images or containing them in a theme then perhaps a move towards an ethical response in the Levinasian sense is possible. I believe *Soft* contributes to the development of new critical frameworks and marks a political/ethical moment worthy of further investigation.

Notes

[1] These comments by Teuben came about in the course of my interview with Gladwin. Teuben was introduced to me by Gladwin and we had a short conversation in which she expressed her ideas about the performance and disability.

[2] Amniocentesis involves the insertion of a needle through the mother's abdomen or through the vagina into the amniotic fluid sack surrounding the fetus (Botkin, 2003:279).

[3] See also Jeffrey Botkin, (2003).

[4] See also Tom Shakespeare, (2002); and Jenny Morris (1992).

References

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Editorial Note

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