When the Baby Breaks:
Exposing the Nerves of Neonatal Bioethics

by:
Jaimie Smith-Windsor
B.A., University of Victoria, 2005

A Thesis Submitted in Partial Fulfillment of the
Requirements of the Degree of

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Supervisory Committee

Dr. Arthur Kroker, Supervisor
(Department of Political Science)

Dr. Warren Magnusson, Departmental Member
(Department of Political Science)
Supervisory Committee

Dr. Arthur Kroker, Supervisor
(Department of Political Science)

Dr. Warren Magnusson, Departmental Member
(Department of Political Science)

Abstract:

Neonatal intensive care is an ambiguous and anxious medicine with troubling un/intended consequences. The causes and increasing prevalence of premature birth, available histories and the establishment hospital-based neonatology are presented, with a particular focus on American and Canadian contexts. The thesis traces neonatal medicine’s unlikely swerve through early-American freakshow culture, considers the influence of the eugenics movement, and spans decades of haphazard clinical experimentation with premature babies. Of particular interest is the complex nexus between neonatology and disability and what new technologies reveal about deep-rooted human desires and fears about life, death and disability. Incorporating statistical data, policy analysis and clinical trends with personal, parent and practitioner narratives leads to provocative ethical questions about neonatology’s growing powers. This thesis draws on critical disability theory and contemporary critical theories concerning technology, and builds towards a conception of disability that is separate from the medical paradigm, somewhat unorthodox, and certainly post conventional.
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List of Abbreviations

AAP – American Academy of Pediatrics
APCFN – American Academy of Pediatrics Committee on the Fetus and Newborn
ART – Advanced Reproductive Technologies
ART – Assistive Reproductive Technologies
BPA – Bisphenol A - phthalate
BPD – bronchopulmonary dysplasia
CP – cerebral palsy
CPAP – continuous positive airway pressure
CPS – Canadian Pediatric Society
DEHP – di(2ethylhexyl) phthalate – plasticizer
DNR – Do Not Resuscitate
FDA – United States Food and Drug Administration
IPPR – Intermittent Positive Pressure Respiration
IVH – Intraventricular Hemorrhage
MEHP – mono-2-ethylhexyl phthalate – plasticizer
NEC - Necrotizing Enterocolitis
NICU – neonatal intensive care unit
NRT – New Reproductive Technologies
PDA – Patent Ductus Arteriosis
RDS – Respiratory Distress Syndrome
ROP – Retinopathy of Prematurity
SCN – Special Care Nursery
TPN – total parenteral nutrition
Acknowledgments:

Dear Quinn,

You’re always asking me to tell the story about when you were born. There are many ways to tell that story and my thesis is just one way among many. Your story begins like this…

We were driving up to the Comox Valley on Vancouver Island when I felt a knock knock knock inside my tummy. We drove to the hospital and the doctor said, “stay put”. But you were determined to be born right there and then and so you were born – 105 days early. They gave you a breathing machine and they put you in an incubator. We touched your hands named you Quinn and a doctor flew you off in the night in the belly of a helicopter. Someone gave you r dad two grainy Polaroid photos of you. The next morning we caught a ferry and came to meet you in the special care nursery. There you were, pink, kicking, swimming in an oversized diaper. When I spoke to you, you turned your head and tried to peek. One day your eyes opened and they were deep and dark, and I knew you’d be our brown-eyed girl. You had such long fingers and boy could you kick! You were as perfect then as you are now.

I loved what those words spoke to me and how they gave me purpose and peace and patience. I was so proud to be your whisperer. So many others were too. How could I ever have believed then what I know now, eight and a half years later? You have become my angel and I, your blade of grass. I learn so much from you each and every day. You are a very good teacher, so keep whispering to me, I’m growing in ways I’ve never imagined just by being your mom.

I’d like to thank you for giving me permission to write about some of our experiences. It’s important to ask questions about why we do the things we do.

I need to thank your brothers, Tazmin and Sullivan, too. They enchant me every day with their clever antics and boundless energy. They really are tremendously inventive and patient. I’m especially thankful they invented “jumpy school”, which they’d play on the bed in the office for hours while I worked on my thesis some days. Without “jumpy school” this thesis would not have been possible. Of course I’d like to thank your grandparents, my mom and dad, Gren and Marg. I couldn’t have asked for more supportive and loving parents. As you know, they are very special people. They’re steadfast in their friendship, values, encouragement, and faith in me.

Quinn, I know you haven’t settled on what you would like to be when you grow up. Take your time – I know you are going to have a magnificent journey! I know this because of the way you imagine the world ahead of you – full of possibility, ready for your invention. On that journey, from time to time you’ll meet people that both inspire and challenge you. My thesis supervisor, Dr. Arthur Kroker, has done that for me. For his constant encouragement and his tirelessly innovative mind I will always be gracious, awed, and appreciative. To Dr. Warren Magnusson I owe similar appreciation, for his patience, candor, rigor and for insisting that I move more patiently, more carefully, more methodically.

Finally, I’d like to thank your dad, Al Osaduik! He’s so unwavering and understanding, always. All those years ago, we waited and waited and waited and whispered over you together – and I fell so deeply and forever in love with him. And with you. And with our whole delightfully unexpected future.

Love, Mom
Dedication:

To all parents of preemies who have spent time in the NICU.
You will understand my often unsettling questions better than anyone.

In Loving Memory of:

L.L. (2005)
Preamble

How soon is too soon? Is there a limit to viability? When is it appropriate to withdraw life sustaining medical treatment from a premature baby? What happens when the baby breaks? It’s one thing to provide unequivocal answers to troubling questions. But it is quite another thing entirely to watch the smallest of babies gasp for breath, or to watch a tiny baby swell with sepsis, or to watch a baby crash, for the last time. It is quite another thing entirely to touch the precariousness of it all and know that uncertainty is the only principle. This is a story about such precariousness and immense uncertainty.

January 31, 2003: The morning you were born, I was doing inventory in the kitchen - weighing spices in the pantry. Marjoram: 1200 grams. Rosemary: 175 grams. Nutmeg: none. And then you. Like Anise: both fruit and seed. New Born Female: 700 grams. We named you Quinn before they wheeled you away in a transportable plastic incubator and flew off in the night.

This is an intimate history of premature birth, and of crossing boundaries:

Yesterday a nurse told me that I could change your diaper for the first time. I had to hold my hands together, like this, to stop them from trembling before I held your ankles between my thumb and my index to lift your legs. I didn’t want you to feel my hands shake. If they trembled you would know that I was afraid for your smallness. My fingers shook anyways, twitching against you, like the wings of a fledgling sparrow, far too young for flight.

It’s about the birth of a cyborg. Who gives life to whom? The machine to the baby? The baby to the machines?1

Today a new nurse tells me that I can hold you in my arms for the first time. The new nurse and two more people in muddy blue scrubs unplug and transfer the limp coils of your ventilator from there to here, plugging the gasping end into a plastic socket in your throat. The breath is forced in, your lungs inflate, and you twitch against my bare chest, twice. But you begin to breathe, again. Or the machines breathe. Or both. The new nurse hovers around us. She pulls your plastic tubing taut around my neck, tapes it down to my shoulder, my thigh and my knee before she allows it to trail off into some machine. There are other tubes, too: more medical spaghetti, bound to my limbs with peach colored surgical tape.

And it’s about consequences and unintended consequences:

Our skins feel warm and moist against each other, except for the places where electrodes are fastened to your skin, with glue. My fingers avoid the place where the nurses’ finger caught and pulled the electrode from your skin, tearing off most of your right nipple.

It’s about the expropriation of wombs and moms by other means:

1 Brodwin, P. (2000) p.218
My nipples, chaffed and cracked from the relentless kneading of an electric breast pump, freely weep milk onto your feet. You fill the valley between my swollen breasts, peek at me through swollen eyelid slits. It is the first time we have looked at each other, our gaze uninterrupted by the plastic wall of an incubator.

Yours ears, without cartilage yet, crumple against your skull. I unfold them with my fingertip; align the tips with your eyebrows, the lobes with your upper lip. There are your eyebrows, curling on your brow, like fallen eyelashes, waiting to be wished upon. I wish and wish and wish, and wish. I can scarcely see your eyelashes. New blood from the newest transfusion has turned your skin a bright shade of blood. Last time, when they pumped new blood into a tube in your ankle, I called you, “my little pimento”. I didn’t think that anyone had heard. But the next day, there it was, draped over the incubator: a handmade quilt with a cocktail olive motif. And I laughed. And I liked the way that laughter sounded in a nursery full of soundless babies and all that living grief.

It’s about equivocal codes of life and death:

Now I read to you a story by Dr. Seuss about Whos who are resilient little people with big hearts. A big elephant has just lost a clover to a sneaky buzzard when a number of alarms sound in the nursery. Baby 6. From across the nursery, the respiratory technician yells: “NO CPR!” This is the first DNR ritual tonight - Do Not Resuscitate. He crosses the room, silences the alarms, switches off the machines. One by one by one: ventilator, oxygen, TPN, incubator, monitors, eight intravenous infusion pumps. The nurse withdraws the tubes, the leads, the sensors, the needles. Beside us, in spot six, another Mother’s baby dies. Another baby dies. This time, there will be no resurrection. There’s a different code for that ritual. And I am taped to a rubberized rocking chair, taped to you, bound to these gasping machines. I cannot leave when another baby’s mother comes to wail good-bye. So I keep telling you my story about little people called Whos amidst the shrill soprano screaming.

And it’s about irony:

A sour but resolute kangaroo has pledged to protect the smallish Whos.

“From sun in the summer and rain when it’s fall-ish, I’m going to protect them. No matter how small-ish!”

And the baby kangaroo, from her pouch says, “me too!”

My words shook the way my hands did when I lifted your wish-bone legs to change your diaper for the first time. And I try not to see the other Mother’s tears caught between her cheek and the invisible shell of an incubator that hides no grief between us. In this moment I know that fiction makes promises to that not every Mother can keep.

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2 Seuss, Dr. (1954) p.72
That was then. And this is now. Nearly nine years has passed since the near-fatal birth of my daughter. The sentience of that experience – her birth and subsequent rescue – is more vivid than anything else I know. Preemie parents will tell you the same. The NICU never leaves you. It haunts.

The aftermath of the NICU may sound a lot like this:

Cerebral palsy
Periventricular lukomalacia
Spastic quadriplegia
Epilepsy
Hemangioma
Bronchopulmonary dysplasia
Retinopathy of Prematurity.  

Or like this:

Social Dysfunction
Low self-esteem
Behavioral Problems
Sleep Disorder
Sensory Hypersensitivity
Cognitive Impairment
Savant traits
Low IQ
Abnormal Reactions to Pain and Danger
Autism or “autistic traits”
Motor skills impairment
Feeding disorders; failure to thrive
Digestive problems; reflux, constipation, g-tube feeding
Gall Bladder disease
kidney stones
bedwetting
Osteopenia (rickets)
precocious puberty
ongoing lung problems: severe asthma
Metabolic Syndrome
cortical blindness
Obsessive Compulsive Disorder
Depression, anxiety, bipolar disorder
Delusional thinking: Schizophrenia
Perseveration Seizure disorders

\[ \text{List compiled from family health records (2003-2011)} \]
Then there is the aftermath of intakes, regular assessments, continuous monitoring reports, referrals, and consultations, appeals for services, surgical fixes, therapies and constant medical surveillance. Intervention after intervention. In our house, they’re categorically filed in a four-tiered metal file box that acts as a monument to the paradigm of perfection and a purely medical model of disability. Annual assessments and reports have become a meticulous history of defects and deficits. They form a library of deviation from ‘normal’ childhood development; each intervention comes with a recommended ‘fix’ or improvement. This is how the medical model of disability sounds, paring individuals down to their well-monitored and documented deficits:

- physiotherapy
- occupational therapy
- speech and language pathology
- orthopedic surgery
- neurology
- cardiology
- neonatal follow-up
- psychology
- nutrition
- ophthalmology & orthoptics
- plastic surgery
- oncology
- developmental pediatrician
- audiology
- social work
- orthotics
- daily living supports assessment
- assistive technology team
- early childhood intervention team
- Otolaryngology
- Community Living
- Pharmacy
- Intensive Needs Pupil Support Services
- Specialized seating
- Respite Worker
- Advocate
- Home Care
- Bloodwork

EEG
ECG

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\(^4\) List compiled from parent reports by Helen Harrison for presentation to the American Perinatal Association (2005)
Available at: http://thepreemieexperiment.blogspot.com/2007/01/outcomes.html
Hepatic Hemangioma
  Repeat Ultrasound
  X-rays
  Botox?
  Surgery

All this because of a little bit of scar tissue. Neonates are haunted by both the residue of medical interventions and a panacea-effect of medical, surgical, pharmaceutical and therapeutic ‘improvements’. The paroxysm of medical and technological interventions available is astounding. The force of this fetish ‘to fix’ babies and children who have disabilities is dizzying. This has to do with the desirable notion of normalcy and the lengths that we go to try to contain, categorize, organize, cure and cull undesirable traits.

This thesis reacts to the incredible paroxysm of desires, medicine and technology that forms the event and aftermath of extreme prematurity and should be read as a meditation of pure uncertainty. As such, it cannot offer solutions to unsettling questions that rise, like specters from the often haunting events surrounding the birth of an extremely premature baby. Rather, it builds towards a conclusion that may be quite unexpected – a conception of disability that will have significant impact on the biopolitics of the future.
Introduction and Methods

When a baby breaks, it is an intimate matter of personal and public concern. This thesis responds to neonatal intensive care and extremely premature birth as both a personal and public matter. In part, it is personal narrative of my experience of giving birth to a micropreemie, the incredible story of her rescue and observations about ‘the aftermath’ of high-tech medical interventions. At times my story mingles with other narratives - those of practitioners, nurses, bioethicists, and other parents. In part these chapters follow an intellectual journey through the complex science of rescuing premature babies, while offering a commentary about babies with manufactured disabilities. It is also a historical sojourn into the origins and future of neonatology and medical progress. Underscoring all of these ‘parts’ is a recurring meditation on disability and normalcy. Rather than disassociating the terrain of personal experiences from the terrain of intellectual work, I embrace both, allowing private matters and public issues to mingle and enrich one another. My personal story and stories of other parents of micropreemies mingle with the empirical stories and data histories that comprise evidenced-based neonatal care, research and bioethics. In C. Wright Mills terms, intellectual craftsmanship is best formulated when personal troubles and public issues share space: when those matters having to do with personal life experiences are made public. “You must learn to use your life experience in your intellectual work; continually to examine it and interpret it,” he says.\(^5\) For, “the problems of social science, when adequately formulated, must include both [private] troubles and [public] issues, both biography and history, and the range of their intricate relations.”\(^6\) It is not my project provide answers to troubling questions, but to adequately formulate them, and, in doing so, contribute to a better

\(^5\) Mills, C. Wright (1959) p.196
\(^6\) Mills, C. Wright (1959) p.226
understanding of my own biography, clinical neonatal practice, bio/ethical dilemmas, modern medical progress, and the available models of disability. It is only then that one’s craft “has its chance to make a difference in the quality of human life in our time.”

The core arguments of this thesis are that neonatology is an ambiguous and anxious medicine, that the consequences and unintended consequences of neonatal intensive care are troubling. The first section of this thesis swerves through the murky past, controversial present and unfettered future of neonatal medicine. Of concern is that preterm birth rates are rising, despite the overall improvement of maternal and fetal health, particularly in Canada and the United States. Of concern is that neonatology is highly experimental and leaves a wake of success and failure, promise and disaster. Secondly, this thesis elucidates the relationship between modern technology, bodies and medicine by blending accounts of the NICU from personal reflection, practitioners and bioethicists. The scene is erratic, uncertain, troubled, and often unfolds quite differently than the general public may think. Neonatal critical care is caught up in a technological drive to improve human reproduction, which has serious consequences for the future. Of particular interest is the complex nexus between neonatology and disability and the possibility that neonatal medicine conceals and reveals deep-rooted human desires and fears; it is as much about staving off death as it is about fearing disability. Incorporating statistical data and clinical trends with personal, parent and practitioner narratives of neonatal medicine and bioethics leads to the articulation of provocative ethical questions and concerns about neonatology’s growing powers. This thesis draws on some of the core assumptions of critical disability theory in order to expand current dialogue about neonatal medicine beyond a purely medical paradigm. At the same time, this thesis productively engages with critical theories concerning technology, specifically Martin Heidegger’s questions concerning technology and Jean Baudrillard’s twin hypotheses of ironic reversibility and the

7 Mills, C. Wright (1959) p.226
The Perfect Crime. These discussions build towards a conception of disability that is quite separate from the medical paradigm. In doing so, this thesis lays the groundwork for engaging more productively with the concept of disability as it asserts itself in and through neonatal medicine.

For over fifty years, hospital-based baby rescue and the treatment of premature babies has been evolving, at once heralded, harangued, lauded and condemned, sensationalized, sanitized, publicized and, at times, wholly misunderstood.\(^8\) Sometimes neonatology is considered to be one of the most successful medical innovations in contemporary medicine. It has become a hallmark subspecialty in contemporary children’s hospitals. To others, it is considered to be “a vast, uncontrolled experiment undertaken without informed consent and with possible undesirable results.”\(^9\) In the eyes of the public, professionals and parents, neonatology is often polarized; it either fulfills a fantasy or is dangerously nightmarish. It might be apt to suggest that it is both. Certainly the evolution of neonatology has followed its own curious curve and ethos: innovations often preceding ethics, critical reflection and open acknowledgement of misadventure. Consider what neonatal bioethicist, John Lantos, says about the evolution of neonatology,

Scientific and technological innovation was so rapid that important questions about the safety and efficacy of interventions could not be conceptualized until the scientific and technological innovations stimulated our imaginations to ask questions. The process of answering questions created new technologies, new understanding, and new questions, which could be answered only by further technological innovation.\(^10\)

In this regard, it might be quite accurate to suggest that we are constantly living in the aftermath of technological innovation and the wake of so-called progress.

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\(^8\) Lantos, J. (2006) p.1  
\(^9\) Maisels, J. quoted by H. Harrison (2001) p.59  
\(^10\) Lantos, J. (2006) p.3
The first chapter of this thesis provides an intense exploration of rising premature birthing trends in the United States and Canada, a trend that is seemingly against the grain of steady maternal and pediatric health improvements. The United States Department of Health and Human Services and the Centers for Disease Control and Prevention, along with the Public Health Agency of Canada report that preterm birth rates are rising. Prematurely born babies that wouldn’t have survived generations ago, now routinely survive. There is little doubt that neonatal intensive care has dramatically improved the survival of critically ill, small and premature babies. For instance, since 1960, the neonatal mortality rate in the United States has dropped from 19/1000 births to 4/1000 births in the year 2000. There may be other correlative trends that are contributing to the rising prevalence of premature birth rates in countries such as Canada and the United States. This chapter explores some of the underlying causes of premature birth, while raising important questions. What is fuelling its growing prevalence? The technological imperative? Professional exuberance, perhaps? The expectation that neonatology will deliver on the rescue-fantasies of doctors, parents and society? Are these highly skilled specialists [neonatologists] responding to needs, or are they creating needs to which they respond?

The evolution of neonatal critical care has taken some surprising detours, not the least of which is the surprising turn the subspecialty made through early-American freak-shows before being professionalized in the hospital environ. Ironically, the professionalization of neonatal intensive care did little to change a culture of controversy that haunts the contemporary practice of rescuing impossibly small babies. A case could be made that neonatology’s strange detour through sideshow culture is reflected in the high-tech environ of contemporary NICUs in the sense that neonatology is still a

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11 Lantos, J. (2006) p.6
pioneering subspecialty that takes place on the frontiers of medicine. It is a wholly fantastical scene: spectacular, unrestrained and extravagant. But how successful?

Clinical innovations in neonatal medicine are often accompanied by catch-22s and haunted by medical mishaps, adverse events, and iatrogenic outcomes. Premature birth and aggressive interventions in neonatology leave a wake of babies with exceptionalities and unknown degrees of disabilities. Boundaries blur when social discomforts surrounding disability bleed into clinical care decisions in the NICU. What happens when social stigmas are reenacted in the NICU? What impact does the social problematization or hystericization of imperfect babies have on the way medical resources are distributed? And what are we to make of the irony that modern medicine is simultaneously eliminating and manufacturing disabled babies?

Chapter two considers the abundance of miracle rhetoric and tropes of medical heroism that help to shape commonly held ideas about baby rescue. Miraculous accounts of neonatology are often at odds with the sober realities of extreme premature birth. It is rather under acknowledged and somewhat contrary to commonly held beliefs about neonatology that rescuing babies is often extraordinarily aggressive and highly experimental, painful, sometimes scientifically haphazard, and even horrific. The outcomes of some treatments are uncertain and sometimes the treatments themselves produce disabilities. Pediatrician and bioethicist John Lantos says, “In the past, cerebral palsy just happened. There was nothing we could do about it. Now it is associated, in many cases, with particular decisions about particular medical interventions that we can choose to use or to withhold.”14 The aftermath of neonatal medicine and the NICU often differs from the miracle rhetoric that fuels commonly-held ideas about neonatology, ideas that seem to stem from some heroic and nostalgic idea about modern medical progress. The residual effects of prematurity and high-tech interventions are astounding and may point

14 Lantos, J. (2006) p.6
to critical flaws in the medical paradigm. What happens when the unintended consequences of aggressively salvaging babies surface and the rhetoric of miraculousness and heroism begin to unravel?

Extremely premature babies are haunted in multiple ways: by the residue of clinical experimentation and innovation, by the technological imperative, by regimes of overtreatment and strategic undertreatment. And, vice versa. Chapter three productively engages with Jacques Derrida and Wendy Brown’s notions of *spectral asymmetry* and *hauntology* in order to consider the ways that borderline babies haunt modern medical progress. Central to this line of questioning is the nexus of disability and neonatology. There are underlying social anxieties about disability that feed into the seductive notion that disability should somehow be jettisoned out of pregnancies and human destiny, altogether. We may be getting dangerously close to achieving this through neonatal medicine and the rapid implementation of new reproductive technologies, generally. Another possibility is that we will fail in this achievement. What if the more we pursue perfection (of human reproduction and bodies), the more it eludes us? Are medicine’s growing powers being subtly eroded by that which it cannot control? Are medical advances responding to or sustaining manufactured social problems in order to offer imaginary solutions? Are technology’s growing power, and our ability to master it, simply an illusion, veiled by the heroic ethos of modern medicine?

One of the many stories that neonatology has to tell is the story of “enslavement to a technological imperative”\(^{15}\) and the expectation that technology will perfect, cure, improve upon, or at the very least, normalize bodies. The technological imperative comes with no guarantee. There is also the possibility that the more we attempt to actualize our desires for normalcy, the more evasive they will become. Neonatology places technological determinism\(^{16}\) under the microscope by drawing on two of

\(^{15}\) Lantos, J. (2001) pp. 23-24
\(^{16}\) Technological determinism refers to the notion that technology shapes social change. See Baker, Jeffrey P.(1996) p. 1
Jean Baudrillard’s hypotheses – the ironic reversibility of all things and the uncertainty principle. The nexus between neonatology and disability, reveals both.

Jean Baudrillard suggests, on the one hand, that through technology unfolds the possibility of creating a culture of extermination that he refers to as the Perfect Crime. If neonatology is any indication, it may also be that we are already living in the wake of the impossibility of the Perfect Crime. The closer we come to the realization of the Perfect Crime (perfection), the more impossible it becomes (imperfection). This is not unrelated to Martin Heidegger’s observation that technology is both a saving power and imminently dangerous. What if the more we strive to manufacture perfect (bodies, babies, pregnancies), the more perfection itself reveals itself as delightful hoax or a parody of human desires for normalcy? What if erroneousness is the surest thing that we can know about bodies? Neither of these hypotheses is mutually exclusive and the possibility that both are equally relevant to the essence of technology in contemporary medical culture underscores the immense uncertainty between technological and human destinies.

This thesis draws from some of the core assumptions that form the foundation of critical disability theory. First, critical disability theory assumes that disability is delightfully irreverent. Different and varied choreographies are simply part of human diversity, and ultimately part of human destiny. In this regard, critical disability theory assumes that an ontological and epistemic shift in the way we think about and socially produce disability is required. Secondly, critical disability theory assumes that the medical model of disability is outdated and that a new model of disability is necessary. Specifically, it relocates the ‘problem’ of disability away from particular impairments and relocates the ‘problem’ in the realm of how society responds to particular circumstances. “Disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion;
rather it is a question of politics and power(lessness), power over, and power to."\textsuperscript{17} Thirdly, critical disability theory shares and seeks out theoretical affinities with other critical theories in a mutually productive way. For instance, explorations of postmodernist and post-structural scholarship contribute to the emergence of critical disability theory, and vice versa.\textsuperscript{18} In the same vein, feminist theory benefits from the integration of critical disability theory, and vice versa.\textsuperscript{19} Finally, critical disability theory moves towards institutional transformation and ultimately towards the development of inclusive societies by refusing the fetish of normalcy and challenging the hegemony of normativism at multiple levels.\textsuperscript{20} What’s argued is that the medical model of disability is limited in its ability to accurately reflect the complexities of the lived experience of disability, in particular, the complex nexus between disability. By drawing from some of the core assumptions of critical disability theory a more nuanced concept of disability emerges that is beyond the prescriptiveness of the medical model.

Some critical disability scholars suggest that disability itself lends itself to the more equivocal underpinnings of the post-structural and postmodern intellectual movements. Indeed, this thesis treats critical disability theory as an emerging thread or ‘niche’ of contemporary postmodern scholarship and assumes that this niche, adequately explored, contributes to a better understanding of both disability and postmodern intellectual frameworks. One of the core assumptions of both critical disability theory and postmodern theories is that our contemporary context is underscored by uncertainty. And, it may be that particular experiences and moments reveal and crystalize things that are rarely and barely discernible, namely, the uncertainty principle itself. For instance, in moments when babies are born beyond the boundaries of possibility and during the subsequent steps that unfold after their precarious births, usual

\textsuperscript{17} Pothier, D. and R. Devlin (2006) p.2
\textsuperscript{18} Corker, M. and T. Shakespeare (2006) p.1
\textsuperscript{19} Garland Thomson, R. (2003)
certainties succumb to vast uncertainty. Objective ironies reveal themselves. In these moments, nothing is black or white. Ethical compasses spin wildly at each decision.

Critical disability theory invites multiple authors, multiple stories, dialogical conversations, autobiographies and personal narratives to contribute to the reconceptualization of disability beyond a purely medical model and apart from the medical paradigm. Critical disability theorists would suggest that neonatal bioethical discourse would be more relevant and productive by adopting a more participatory method of inquiry, one that includes interdisciplinary contributions and incorporates multiple and diverse voices, experiences and expertise. In an attempt to contribute to the existing body of neonatal bioethics and critical disability theory, this thesis uses mixed and multiple methods of inquiry. Blending statistical data and clinical research findings with personal, parent and practitioner narratives of neonatal medicine and bioethics leads to the articulation of provocative ethical questions and concerns about neonatology’s growing powers. This thesis draws on some of the core assumptions of critical disability theory. At the same time, it is productive to engage with critical theories concerning technology, specifically Martin Heidegger’s questions concerning technology and Jean Baudrillard’s twin hypotheses of ironic reversibility and the uncertainty principle. These discussions build towards a conception of disability that goes beyond the medical model and all that is implied with its prescriptive assumptions about disability and normalcy. Ultimately, this thesis lays the groundwork for engaging more productively with the concept of disability as it asserts itself in and through the high-technologies of infant rescue.

We know already that questioning builds a way\textsuperscript{21} forward for the intellectual imagination. We also know that by making private troubles public, the intellectual imagination is excited and there is a

\textsuperscript{21} Heidegger, M. (1977) p.3
chance to make a difference in the quality of human life in our time. Where medicine is sometimes incongruous with its own intellectual framework and scientific objectivity, Arthur Franks suggests that it “seems more useful to open up the discourse” than it does to offer guidance. Ultimately, this thesis aims to open up discourse to greater complexity and questioning surrounding neonatology and disability and their complex interdependence. What is important is the act of opening up discourse about bodies and disabilities to their own complexities.

It is too much to expect philosophy to solve ethical problems, just as we expect too much of ethics if we expect it to offer unequivocal delineation between acceptable and unacceptable moral choices, or definitive “rights” and “wrongs”. To search for ethical lucidity in the context of neonatology only reveals deep-rooted ironies and uncertainties about the limits and limitless nature of technology, medicine and bodies. What the philosopher’s task is, what the ethicist’s task should be, and what the critical theorist’s challenge is, is to commit to discourse, to build a way forward through questioning. As such, this thesis does not proffer clear cut answers to stated problems, but seeks to broaden the scope of existing discourse about neonatology, and, more generally, about the relationship between scientific progress, medical innovation, economics, human reproduction, bioethics, policy, and the Pyrrhic victory of neonatology.

22 Mills, C. Wright (2000) p.226
Against the Grain:  
The Evolution and Expansion of Neonatal Intensive Care

This chapter explores the causes and increasing prevalence of premature births, available histories of prematurity and the establishment of the high-tech neonatal intensive care in modern day NICUs, with a particular focus on the evolution of neonatology in American and Canadian contexts. By way of exploring changing and correlative trends in premature birthing and neonatal intensive care practices, this chapter considers two inter-related possibilities; first, that the increasing prevalence of premature births may related to changing reproductive technologies and maternal care practices and second, that the neonatal intensive care industry is both the cause and effect of the issues it sets out to solve – namely high risk pregnancies and high-risk births.

Neonatology is full of surprising turns, historical and otherwise. It’s often dubious and spectacular history as a side-show spectacle is both curious and telling. This chapter explores neonatology’s unlikely swerve through the early-American sideshow circuit and traces the evolution of the baby-rescue industry through the past century of progress. A critical analysis of medical progress in the field of neonatology raises provocative ethical questions and concerns about neonatology’s growing power today.

In developed countries such as Canada and the United States, medical care over the past 40 years has advanced dramatically so that many more babies are now born in good health, and fewer babies die in their first year of life. Before the 1960s, few problems could be diagnosed in pregnancy and very few treatments could be offered to babies born very early or very ill. Most of these babies would die and
consequently, ethical issues in fetal and neonatal care were less common.” Clearly the ethical turmoil is not that neonatology has been successful in lowering the incidence of infant mortality, or that more babies are surviving with the help of medical innovation. These are the undoubted successes of neonatology. So why is there a sudden and growing amount of interest about the “ethics” of neonatology? Ethical tensions are rising because of the differential and unpredictable outcomes of prematurely born babies who receive aggressive medical interventions. Some survivors grow into normal childhoods, and other survivor’s childhoods are overshadowed with significant health sequelae related to their preterm births and rescue. Arguably, disability is the unintended consequence of the exuberant interventions that attempt to intercept babies from more immanent, ‘black or white’ biological rituals: living and dying. Assumedly, if disability weren’t a common outcome for preemies and micropreemies, there would be little, or far less heated debate surrounding the merits of neonatal medicine.

Pointing Fingers: The Prevalence, Prevention and Causes of Premature Births

The prevalence of premature births in most industrialized countries is increasing\textsuperscript{27}, despite the widespread availability of advanced maternal and prenatal care and surveillance programs. There is a wealth of statistical data that traces this trend over the recent past in countries with industrialized health care systems. According to the United States Surgeon General, premature birth rates increased from 9\% of total births in the United States in 1980 to 12\% of total births in 2002. The increasing prevalence of preterm birth rates is significant. According to national vital statistics, since the early 1980s, preterm

\textsuperscript{26} The Nuffield Council on Bioethics (2006) p.33
birth rates have increased by 36%. Subsequently, National Vital Statistics demonstrate that the trend has continued. In 2006, the preterm birth rate rose to 12.8% of births. As such, preterm birth is considered a growing health problem in the United States.

A similar increase in Canada’s preterm birth rate has been reported by the Canadian Perinatal Surveillance Program. The 2003 Canadian Perinatal Health Report suggests that rates of preterm births have steadily increased from 6.6% of live births in 1991 to 7.6% of live births in 2000. Data available in the 2008 Edition of the Canadian Perinatal Health Report shows that the preterm birth rate has increased from 7% of live births in 1995 to 8.2% of all live births in 2004. The trend continues. Figure 1.1 illustrates the steadily increasing rate of preterm birth in Canada, per 100 live births over a ten year span. The Canadian Perinatal Report also shows that the preterm birth rate of twins is 57% and that 96.1% of higher order multiple births are born premature. The highest preterm birth rate in Canada is in Nunavut, where 12.2% of all live births are considered preterm. Increasing rates of prematurity are being met with increasingly heroic or aggressive measures and medical interventions that aim to save younger and smaller babies from otherwise immanent death. Prematurity continues to be the leading cause of infant death, disability and obstetric intervention in Canada and the United States.

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29 Martin, J.A. (2008) p.18
Born in 1985, a baby weighing less than 500 grams at 22 weeks of completed gestation would have been considered stillborn. Born today, this baby will likely be born ‘live’, become the beneficiary of ‘extra-heroic’ medical interventions, and enter into the strange, ethical and medical fracas known as the Neonatal Intensive Care Unit – the NICU. Born today, this baby would have a reasonable chance of survival. For this new category, created for babies who’ve breached the boundaries of biological possibility, survival rates continue to improve. Since 1985, the neonatal death rate in Canada has been reduced by half.\textsuperscript{35} Rising rates of prematurity may also be related to the industry trend to resurrect more babies that would not be considered “viable” (read: livable) even a few years ago. Premature babies are now being resuscitated as early as 20-21 weeks of gestational age in some NICUs, at the discretion of practitioners and parents and in the absence of binding legislation and regulations that

\textsuperscript{34} This data does not include preterm birth rates from Ontario. Figures based on Vital Statistics are available in the Canadian Perinatal Health Report (2008 Edition) p.124

\textsuperscript{35} See Appendix F, Table F1.A. Canadian Perinatal Report (2008) p.216
clearly delineate the viability of babies born too soon.

Confounding the possibility of establishing clear parameters around “viability” is a quagmire of therapeutic and late term abortion policy and litigation. Most developed countries establish the legal limit for therapeutic late term abortions at 24 weeks of completed gestational term. This means that aggressive neonatal interventions are salvaging babies born weeks before the limit of viability dictated by policy and law relating to late-term abortion and therapeutic termination procedures. The possibility of establishing a clear biological limit of viability is dubious. Partly because there is no clear limit in legislation, regulations or law, the limits continue to be pushed. Babies that are born 147 days into a 280 day pregnancy are being resuscitated and sustained outside of the womb, with varying rates of survival. By continuing to push the threshold of viability, neonatology has created more of an industry of child-rescue for itself. So, it may not simply be that the prevalence of premature birth is increasing, but that an unfettered neonatal industry, lacking guidance on a clearly defined ‘limit’ to viability, continues to push the boundaries by routinely resuscitating greater numbers of younger and smaller babies.36

The established standard of practice in neonatal care today (in North America and abroad), is to resuscitate babies who are borderline, survey their progress, wait for the baby to ‘declare themselves’ as viable and ‘intact’ after initial technological intervention. Once declared intact and viable, practitioners and families make a decision whether or not to continue with or cease treatment.37 In the best interests of identifying causes and prevention strategies for premature birth trends, critical reflection of the health

37 The Fetus and Newborn Committee of the Canadian Paediatric Society and the Maternal-Fetal Medicine Committee of the Society of Obstetricians and Gynecologists of Canada recommends that fetuses born prior to 22 weeks of completed gestation are not viable. Those born at 22 weeks are rarely viable. There is a high degree of viability with fetuses delivered between 23 and 24 weeks of completed gestation. See G. Miller (2007) p. 106-107. This is in keeping with established international guidelines for neonatal resuscitation which suggests 23 weeks of completed gestation serve as the cut-off threshold for determining which babies should receive aggressive medical interventions. Resuscitation, it has been argued, has become the preferred response in the delivery room, as it does not necessarily mandate continued support. See G. Miller (2007) p. 127.
industry as a whole needs to take place. The routinization of neonatal resuscitation for borderline babies might contribute to the increasing prevalence of premature birth and extreme prematurity. By creating its own demand, the industry might be conditioning an expansionist future towards some ill-articulated goal in the name of medical ‘progress’. Where is this all heading?

What forces babies from the womb too soon? “Today, when families ask why their baby was born early, most of the time, the only answer the doctor can give is…we don’t know.” This may be an oversimplification. Prematurity is considered to have a multifactorial etiology. Put simply, there are multiple and sometimes inter-related causes of preterm birth which make it difficult to provide a single and precise reason. The known and suspected causes are social, environmental, biological and systemic. Family history of prematurity seems to be the best predictor of premature labor, which is associated with short cervical length, which is, in turn, associated with shortened gestational term. ‘Incompetent’ cervix is a commonly diagnosed condition which may result in preterm labor. Both short cervical length and ‘incompetent’ cervix are thought to be genetically inherited traits, although women who have been surgically treated for cervical cancer or pre-cancerous viral cells may develop one or both of these characteristics. Maternal infection, Placenta Previa and preeclampsia are high risk conditions that often result in spontaneous labor or early, emergency induction of premature labor. Other important risk factors may include; severe dehydration, stress, low body weight or malnutrition, history of abortion, smoking, environmental causes, or drug abuse. The link between advanced maternal age and premature labor and delivery has also been well-established.

40 National Institute of Child Health and Human Development (2001)
There is some emergent evidence to suggest that rising rates of preterm birth may be related to increasing levels of exposure to plasticizing chemicals found in everyday products. For example, chemical plasticizers known as phthalates are under investigation by the FDA and Health Canada to determine the extent to which high exposures cause teratogenic outcomes and reproductive toxicity. Phthalates such as di(2-ethylhexyl) phthalate (DEHP) and Bisphenol A (BPA) are plasticizers commonly used to create durable and flexible pvc piping, vinyl, medical equipment, epoxy, toys, plastic containers and other common items. Exposure to phthalates is universal to all humans. Although the general adult population is not deemed to be at high risk for toxicity, there are particular groups that experience elevated risks including pregnant women, infant and pediatric patients. Neonate, infant and pediatric patient groups are highly exposed to DEHP in medical equipment during common medical procedures including: respiratory therapy, total parenteral nutrition, ventilation, blood transfusions, catheterization, etc.\(^4\) Health Canada and the US Food and Drug Administration both report concerning evidence that male patient groups, in particular, are being overly medically exposed to plasticizing chemicals found in common medical equipment and could be at risk of acquiring testicular toxicity.\(^5\) Male neonates and pediatric groups are particularly at-risk. There is some evidence to suggest that toxicity caused by plasticizing phthalates may be related to toxicity-induced late term miscarriages resulting in live premature births, especially among male babies.\(^6\) According to researchers Latini, et

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\(^5\) Medical Devices Bureau, Therapeutic Products Directorate, Health Products & Foods Branch, Health Canada. DEHP in Medical Devices: An Exposure and Toxicity Assessment, Draft Report, Ottawa, Canada (Revised, February, 2002).

\(^6\) US Food and Drug Administration, Center for Devices and Radiological Health. Safety Assessment of Di(2-ethylhexyl)phthalate (DEHP) Released from PVC Medical Devices. Rockville, MD: Center for Devices and Radiological Health; 2001

\(^7\) Medical Devices Bureau, Therapeutic Products Directorate, Health Products & Foods Branch. Health Canada. DEHP in Medical Devices: An Exposure and Toxicity Assessment, Draft Report, Ottawa, Canada (Revised, February, 2002).

al., as many as 88% of newborn cord blood samples contain DEHP or its active toxic metabolite MEHP.\textsuperscript{49} Their research also establishes an important link between phthalate toxicity and preterm birth. The unintended consequences of manufacturing an increasingly synthetic world may be toxic.

Much research is devoted to linking poor maternal socioeconomic status to premature labor.\textsuperscript{50, 51} Geoffrey Miller claims that, “those [women] with lower socioeconomic status were at higher risk for a poor perinatal outcome. There is a strong association between preterm birth and social disadvantage.”\textsuperscript{52} The preterm delivery rate is nearly double in the United States than in Canada or Western Europe.\textsuperscript{53} Arguably, this trend is indicative of systemic causes of preterm birth patterns. Interestingly, Miller doesn’t associate a ‘poor’ maternal socioeconomic profile to endemic health disparities and fettered access to quality medical care for disadvantaged populations as risk factors for preterm birth in the context of the American healthcare industry.

The often studied link between socioeconomic status and preterm labor has resulted in a barrage of maternal education campaigns, health literacy programs, and greater medical surveillance programs in the United States and Canada. Yet, neither maternal education campaigns, nor total medical surveillance (for those who have access) will effectively change the underlying economy of disparity and exclusion that exist within the American health system, in particular. Exclusion from basic prenatal health care on the merits of socioeconomic disadvantage contributes to the incidence of preterm birth by creating economic barriers to securing healthier pregnancies. Curiously, with regards to premature births, it is “almost as if society, by some mechanism, were working against health, and medicine were

\textsuperscript{49} Latini, G. et al. (2003)  
\textsuperscript{50} Lantos, J., W. Silverman and G. Miller (2007) p. 196  
\textsuperscript{52} Miller, G. (2007) p. 196  
\textsuperscript{53} Miller, G. (2007) p. 196
then working against the rest of society, separately trying to patch the wounds caused by some nameless thing that forces babies from the womb too soon.”

Rates of preterm birth and infant mortality rates are also organized around racialized categories. In the United States, for instance, “mortality rates for black infants is twice as high as that for whites and there are similar differentials within the white population: the highest rates are found among those on the lowest rungs of the socio-economic ladder.” Likewise, the correlation between social disadvantage and preterm birth, as well as Aboriginal status and preterm birth has been established in Canada. According to the Canadian Perinatal Surveillance System in 2000, the preterm delivery rate in Nunavut (with a predominantly Aboriginal population) is 10.6% compared to the national average of 7.6% of total live births. These trends are often met with maternal education campaigns, which associate the ‘problem’ of preterm birth as an event caused by particular individual characteristics and circumstances rather than a symptom of systemic health inequities. In the U.S.A., for instance, campaigns to prevent premature birth are targeted at vilified, often racialized mothers, through maternal education programs rather than acknowledging the exclusionary effect of the health system which awards access to health on the merits of ‘capital’ and, subsequently, ‘race’.

It is therefore necessary to consider possible systemic reasons for rising preterm birth rates. Socio-economic disadvantage and manufactured health disparities create differential access to adequate medical care between different groups. Why is it that the highest rates of preterm birthing occur in North American Indian, Inuit and African American pregnancies? These trends are unexplained by

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54 Lantos, J. (2001) p. 119  
existing research and further research is required to explain this phenomenon in both Canada and the United States. First, it might be productive to explore the correlation between preterm birth rates and poverty amongst North American Indian, Inuit and African American mothers, in particular. Second, it might be productive to consider the correlation between preterm birth rates and the availability/accessibility of quality medical care for North American Indian, Inuit, and African American mothers. It may be significant that lower rates of preterm birth occur in Canada, as compared to the United States. What accounts for this difference? It’s possible that marginalized socio-economic groups in Canada have better access to a medical care system than their American counterparts. The Canadian Public Health Agency recognizes that although health disparities exist in Canada, universal access to health services mean that pregnant women receive high quality maternal care.

Causes for rising rates of prematurity may be due, in part, to social reasons. Health policies, public health prevention strategies, prenatal health literacy and education campaigns have largely mobilized around the social problematization of marginalized groups and women: African American and American Indian mothers, single parents and working mothers, remote, traditional Aboriginal mothers, teenage mothers, the economically disadvantaged or those with low education levels. Interestingly, despite known risks associated with pregnancy during advanced maternal age, the increasing use and availability of Advanced Reproductive Technologies, and the increasing prevalence of multiple births, educational campaigns continue to target socially problematized individuals and

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groups rather than women with advanced maternal age, or the growing number of couples who actively seek out various methods of artificial conception. Generally speaking, there is widespread public acceptance of the trend to have babies later in life and a greater acceptance of artificially conceived pregnancies. In the thrust of biomedical progress and achievement, the industry has yet to turn a serious critical eye on its own complicity in rising rates of prematurity via high-tech infertility treatments and aggressive obstetric and neonatal interventions.

The growing prevalence of Advanced Reproductive Technologies and Assistive Reproductive Technologies (ARTs) are not only responding to rising rates of infertility, but they may also fuel the growing rate of premature birth. Among other contributing factors, research conducted by Robert Goldenburg (et. al.) relate high rates of preterm delivery with artificially conceived pregnancies. The Public Health Agency of Canada reports that the use of assisted conception methods has resulted in both rising rates of multiple births and rising rates of premature birth in Canada. In response to expounding rates of medically intervened and assisted procreation, the Canadian government is currently developing regulations around the use of ARTs, but in the meantime, reproductive legislation is uncertain. Commonly used Assistive Reproductive Technologies include invitro fertilization, egg implantation, and the use of fertility drugs, but the term includes all procedures that help people build their families. Often, the use of ARTs results in the fertilization of multiple eggs. Multiple eggs yield

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68 Among other Advanced and Assistive Reproductive technologies, in vitro fertilization, egg implantation and the use of fertility drugs are doubly associated with multiple births and prematurity. In 2006, Assisted by fertility drugs, Canada’s first known sextuplets were born to an anonymous couple after the parents “refused selective reduction, which would have terminated some fetuses to improve the chances of the others.” The six babies were born at 24 weeks gestation, two of whom died within a week. The case was cause for much media attention due to the couple’s refusal of blood transfusions for their six children, based on their spiritual beliefs as Jehovah’s Witnesses. See Dyer, Owen (2007).
69 Goldenburg, Robert, et al. (2008) pp. 74
71 Cook, J. et. al. (2011) p. 610
multiple births. These pregnancies account for a large proportion of preterm births.\textsuperscript{72} In 2006, researchers report that more than 30\% of pregnancies that used ARTs resulted in twins or higher order multiple births in Canada.\textsuperscript{73} The high-risk nature of prematurity is well established in Canada, where prematurity is the primary cause of infant morbidity and disability. Over 70\% of neonatal deaths and 75\% of neonatal morbidity are associated with prematurity.\textsuperscript{74} This trend is magnified amongst pregnancies of twins and multiples and rising rates of multiple births created by ARTs. More than half of neonates born through ARTs are multiple order births.\textsuperscript{75} Perinatal mortality rates are four times greater amongst twins and six times greater amongst higher order multiple births, as compared to singleton births.\textsuperscript{76} Furthermore, the prevalence of cerebral palsy (and other health sequelae) associated with prematurely-born multiple births follow similar trends.\textsuperscript{77} Research exploring the complex relationship between ART, multiple births, prematurity, neonatal death and neonatal morbidity are raising new questions about the safety, efficacy and ethics of ARTs, underscoring the drive for policy development in this area.

In the United States of America, the Department of Health and Human Services and the Centers for Disease Control and Prevention report increasing prevalence of pregnancies that involve ART, and a correlative increasing prevalence of twin and multiple births.\textsuperscript{78} In 2008, 3.2\% of live births in the United States were twins or multiple births. Rising rates of twin and multiple births are associated with increased use of assistive human reproductive technologies. The 2005 Assisted Reproductive

\textsuperscript{72} Public Health Agency of Canada “Make Every Mother and Child Count: A Report on Maternal and Child Health in Canada” (2005) p. 5
Technology (ART) Report states that up to 32.9% of pregnancies which involved ART resulted in pregnancies with twins and as many as 4.4% of assisted pregnancies resulted in the birth of triplets or higher order multiple births. These figures represent a dramatic increase in: the number of medically manufactured twin births, multiple births, and both live multiple births and unsuccessful multiple births at a national level. They also reflect a growing demographic of high-risk babies being born each year. Nationally, the overall number of ART assisted pregnancies involving women over the age of 35 are also significantly increasing, according to the report.

The same trend can be found in Canada where the birth rate of multiples has risen to 3% of all births, according to the Canadian Perinatal Health Report, 2008. Canada, along with the United States has one of the highest rates of multiple births, globally. Advances and increasing access to Advanced Reproductive Technologies and assisted procreation has resulted in an interesting paradox. Paradoxically, in order to ‘fix’ high-risk or difficult pregnancies, more high-risk babies have to be born.

The use of fertility drugs resulting in the live births of octuplets born in California at 30 weeks gestation in January of 2009 has recently brought to the fore some of the ethical dilemmas associated with widely available, state funded fertility treatments. The prematurely born Californian octuplets are only the second set of eight babies, born at the same time, to complete such a lengthy gestation, survive more than a few hours and experience relatively minimal medical intervention. Of Canada’s first sextuplets, born at 25-weeks of gestation in Vancouver in January of 2007, two died. The California case is currently under investigation by the California Medical Board. The heightened risks of death, disability and health sequelae associated with prematurity, combined with a near non-existent policy framework are bringing the unbridled use of ARTs into question in many countries. Infertility

treatments and the role of fertility clinics have redefined the very terms of human procreation, leaving ethicists to navigate the mire of questions which ARTs provoke. Should fertility treatments be publicly funded? Are they worth the ‘risk’? Does the treatment of infertility respond to the state-given ‘right to bear children’? What are the consequences and unintended consequences of redefining human procreation?

Existing data about the phenomenon of rising preterm birth rates reveals multiple and interconnected trends; rising rates of multiple births associated with ARTs, underlying health disparities, differential access to health care services, environmental causes, and toxicity. Available statistical data provides a clear picture of recent preterm birth trends in industrialized countries such as Canada and the United States. Associated with growing rates of prematurity and rising rates of multiple births in Canada, the Canadian Institute for Health Information reports that a growing number of babies are being born below 2500 grams.\(^8\) It’s important to recognize the limitations of existing statistical data, however. Rising rates of prematurity are not a new phenomenon and may even be historically insignificant in consideration of the transformation of birthing, human reproduction, and medical practices over centuries. Presumably preterm birth rates have been rising for a much longer continuum, as birthing practices have transformed and infant mortality rates have improved. There is not adequate comparable data of preterm birth rates prior to 1980. Current data provides little opportunity for comparative or far-reaching historical analysis. For instance, there is limited comparable data available on preterm birth rates in countries with less developed health services and medical care. It’s important to acknowledge the limited usefulness of available literature on prematurity and statistical trends.

So, in some ways, existing data about rising preterm birth rates and changing medical practices is

extremely limited and limiting. On the other hand, there is a great deal of information being produced about a very small group of people, who are born at a particularly small window of history and medical progress. In a contemporary historical context, incredible efforts are underway to create a more credible evidence base for neonatology and to curtail growing concerns about the cost and effectiveness of rescuing high-risk babies from otherwise certain death due to extreme prematurity. Since the 1980’s, glutinous amounts of data about prematurity have been produced and continue to be produced. It’s estimated that the annual amount of published biomedical literature has been increasing at a rate of 6-7% each year.\(^8\) In his book *Where’s the Evidence? Debates in Modern Medicine*, neonatologist William Silverman explores the role, relevancy and credibility of data to clinical practice. The crux of his argument is that we’ve become very good at producing mountains of data about bodies and less adept at wielding that data usefully in clinical practice. Of particular concern to him is the growing amount of flawed methodological research and ir/replicable research that currently informs clinical practices in neonatology. While information scarcity is being replaced by information obesity, the credibility of clinical evidence, methodology and the peer review process is being increasingly called into question.\(^\text{83}\) Silverman asks,

How can readers cope with this unprecedented glut of data – the flood of text, numbers, tables and graphs that gushes forth from the word processors of a growing army of busy medical writers?\(^\text{84}\)

Silverman warns, “that we should not minimize the daunting problem of evaluating the validity of evidence set out in the electronically-available glut of raw data…there is a danger that lurks in this new Age of information.”\(^\text{85}\) Put simply, there is danger in giving available ‘data’ about prematurity a

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totemic or dogmatic quality. So we must go beyond the limits of statistics, available data and existing literature to explore the full implications of premature birth.

In its limited way, existing data around premature birth trends, raises important questions. From questions stem the revelation of ironies – that in trying to fix pregnancies, more high-risk pregnancies and births occur. The babies now born beyond the boundaries of human procreation hover in significant ethical vertigo. Clearly, there is no one single and easily identifiable cause of premature birth. Rather, the causes are multiple, interrelated and accompanied by ethical query, quandary and complexity. The phenomena may be best explained by looking at interrelated trends, specifically in Canada and the United States: rising rates of premature birth, increased use of Assistive Reproductive Technologies resulting in multiple births, environmental toxicity, prevailing health disparities amongst socially and racially marginalized mothers. It’s curious that in two countries with highly advanced medical care available, that more and more women continue to have preterm babies. This trend cannot be explained by pointing towards maternal incompetency and environmental causes alone. Self-critical questions of the neonatal and assistive human reproduction are beginning to surface. Does the failure to curb and self-regulate unbridled biomedical experimentation in maternal bodies neonatal patients contribute to the global trend of rising preterm birth rates? Is the biomedical industry creating, or at least contributing to its own health crisis by fuelling its own ever-expanding appetite to use ever-more aggressive technological and unfettered biomedical interventions on ever-smaller and gestationally younger babies?

The live birth rate continues to rise in Canada. Between 1985 and 2004, the number of live births has increased threefold among babies born on the border of viability, those with birth weights less

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than 500 grams.\textsuperscript{88} The trend is significant, suggesting that three times as many babies born at the extreme borderline of viability are considered viable as compared to twenty years earlier. A significant decline in infant mortality accompanies this trend. For instance, between 1991 and 2003, the infant mortality rate among prematurely born babies with low birth weights has decreased by 40%.\textsuperscript{89} Simply put, more babies who are born at the extreme borderline of viability are surviving. General birthing patterns in Canada show that babies are being born at a time when neonatal mortality rates have never been lower and live birth rates have never been higher. These favorable trends have at least one unintended consequence; many borderline babies survive and experience lifelong health sequelae as a result of their premature births.

Contemporary neonatology continues to push the limits of viability by treating smaller and gestationally younger babies – babies that would otherwise miscarry or be stillborn. In doing so, NICUs themselves may be contributing to growing rates of preterm birth in Canada and the United States, specifically. This, of course, raises dubious questions about the industry itself. Is neonatology self-prophesizing? Are NICUs in the western health industrial complex expanding capacity to meet the need for more neonatal intensive care, or are they creating that need by treating more babies than ever before? John Lantos says, “To a certain extent, neonatal intensive care has become necessary because we have created a society that produces a lot of premature babies.”\textsuperscript{90} Arguably, vice versa. Premature babies are necessary because we have created such advanced neonatal intensive care. Why is this so? Amongst many possibilities, I will mention three.

First, neonatology is fuelled by the technological imperative – the expectation that humans possess technology so powerful it can improve, fix, cure and cull all error from pregnancies and bodies.

\textsuperscript{88} Public Health Agency of Canada, Canadian Perinatal Health Report (2008) p.10
\textsuperscript{90} Italics added. Lantos, J. (2001) p. 119
In other words, neonatology is expanding because we invest technology with our expectations, will it to power, and feel entitled to it – whether it is wholly effective or not. Our expectations fuel technology and vice versa.

Second, neonatology is expanding because we, as a society, are seduced by the possibility of becoming normal, or better, or perfect and are equally anxious about difference, error and ambiguity. In other words, it is expanding because society has elevated expectations of bodies and babies. It is expanding because we have become anxious about biological procreation. Neonatology responds to that expectation and that anxiety. And vice versa. Anxieties and expectations are heightened because of neonatal responses.

Finally, neonatology is a big industry. So it expands. The phrase neonatal industry warrants explanation. Neonatology is like an industry, because someone profits. This is evident in the American health care system, which is driven by for-profit incentives. Neonatologist, William Silverman, draws a similar parallel between the theatrics of the early-American side show and the dramatic environment of contemporary neonatology. Both are quite detached from reality and, in both cases, extreme measures to save premature babies are undertaken in a context where someone profits. The moral imperative to rescue borderline babies is shaped “within the infrastructure of economic arrangements.”

Undoubtedly, “economic arrangements” complicate administrative and clinical decision-making processes in NICUs. Consider one father’s remarks:

There’s a motive for a for-profit health care giant to choose and make decisions for aggressive treatments…When Sidney was in the NICU, everything was on barcodes. If they used a syringe, they recorded the bar code on Sidney’s chart. I saw them bring barcodes from stuff they used on indigent children and put it on Sidney’s chart. We got charged $35 for a circumcision tray. I’m going to go out on a limb and say I’m pretty sure my daughter didn’t get a circumcision. It was

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the hospital administrators who made the decisions for our child. They made them over our objections...[they] picked my daughter’s care...They depleted our one-million dollar [insurance] policy and walked away from their decisions.93

Arguably, NICUs thrive and expand because someone profits.

The extent to which NICUs operate like a profit-driven industry is evident the way that (largely American) pharmaceutical companies and interests play out in NICUs. Pharmaceutical companies benefit from unfettered profiteering. Many NICU pharmaceuticals are considered “orphan drugs” or are produced by companies that enjoy market exclusivity. Exorbitant drug pricing is the most obvious effect. Multilateral pharmaceutical policy agreements, artificially inflate drug pricing in jurisdictions outside of the United States.

Orphan drugs are “new chemical entities, known drugs which have never been approved for a known indication, or drugs which were once approved but have now been withdrawn from the market.”94 Typically, they are drugs that are used to treat rare or ‘orphan’ diseases. Preemies, as a relatively small and under researched patient group, bear the benefits and burdens of orphan drugs and bad orphan drug policy. It is not uncommon for orphan drugs to have egregious prices, and profits. Consider the neonatal drug indomethacin. In 2005, Ovation Pharmaceuticals Inc. purchased exclusive rights to manufacture and sell the ‘orphan drug’ indomethacin, which is used to treat a condition of prematurity known as “patent ductus arteriosus” (PDA), a common, yet correctable heart condition “that prevents holes from healing in the hearts of premature infants”95. The drug, under the name Indocin I.V. has been used as an alternative to surgical intervention to correct heart problems in premature babies. After Merck Pharmaceuticals sold the drug in 2005, “Ovation increased the price of the drug more than

94 dePaulsen, N. p.1
95 Klobuchar, Sen. A. Press Release (March 08, 2008) The same drug is available in Canada at a price 44 times less than what is currently available in American Neonatal Intensive Care Units.
18-fold – from $100 to $1,875 for three one-milligram units of the drug.”

Ovation secured a complete monopoly over the so-called ‘orphan drug’ by also buying out the patent rights to its sole competitor NeoProfen. After Ovation acquired NeoProfen, the price of NeoProfen was also artificially inflated by some 1300%. NeoProfen and Indocin remain the only two FDA approved drugs available for treatment of heart failure in neonates. Without competition or constraint, or adequate multilateral orphan drug policy, pharmacology bills for neonates who rely on ‘orphan drugs’ in critical care will continue to be abhorrent.

Ovation has also recently acquired exclusive rights to manufacture Diuril Sodium. Diuril Sodium is a diuretic used to treat fluid overload in neonates. Ovation’s pharmaceutical acquisition was accompanied by an overnight price increase of 864% per dose. Acthar, a ‘captive market’ Questcor drug used to treat infantile spasms witnessed a price inflation of 1310% after purchase. Similarly, orphan-drug Cosmogen, used to treat leukemia and pediatric lymphomas increased 3437% after being acquired by Ovation. It is no wonder that the Pharmaceutical Drug firms, especially those that specialize in orphan drugs, have topped all other Fortune 500 companies in recorded company profits for thirteen consecutive years.

Another example of profiteering in neonatology can be seen in the rapid expansion of for-profit corporate medical groups in the United States. The high-cost care of rescuing premature babies that is absorbed by American taxpayers often raises questions about the justification of the highly subsidized

96 Klobuchar, Sen. A. Press Release (March 08, 2008)
subspecialty. The underlying question seems to be – given that the costs of disability associated with prematurity are so high, is neonatology ‘worth’ it? Strangely, there are relatively few questions that swirl about ever-increasing profit margins realized by for-profit corporate medical groups in the United States. “For-profit medical groups have evolved particularly in the technology-intensive, hospital-based specialties such as radiology, anesthesiology, emergency medicine, and neonatology.”99 For example, Pediatrix Medical Group Inc. is one of the fastest growing corporations in the United States of America, currently providing hospital-based neonatal services in over 275 American and Puerto Rican hospitals. According to the Securities and Exchange Commission, the Pediatrix network employs over 600 neonatal physician specialists and hundreds of other hospital based pediatric specialists”100 The Pediatrix Medical Group Inc. also founded a subsidiary corporate medical group for hospital-based obstetrics called The Obstetrix Medical Group.101 In 2009, Pediatrix began buying out anesthesiologist practices nationwide, which has increased the corporation’s appetite to expand, eliminate competition, enjoy a monopoly of power, increase revenue-potential, and guarantee the commercial interests of hospitals.

Pediatrix Medical Group Inc. is registered with the New York Stock Exchange under the trade name MEDNAX or ‘MD’. MEDNAX continues to record profits and unprecedented growth. MEDNAX recorded a revenue increase of 24% in the first quarter of 2008 over the previous year.102 The company’s fourth quarter revenues for 2009 show a profit increase of $12.6%.103 Interestingly, patient volume follows the same trend of expansion.

MEDNAX executives are awarded MD stock as performance bonuses and the for-profit medical group awards stock to their employees. This means that neonatologists, pediatric cardiologists and anesthesiologists are both, simultaneously, shareholders and caregivers. Shouldn’t it be cause for concern that a neonatologist maintains financial interests in his subspecialty when considering the treatment options available to a baby with a litany of compromised organs? The profiteering nature of neonatology raises some unsettling questions about the neonatal industry.

Finally, neonatology is like an industry because it requires significant investment of medical resources. It clearly operates in accordance with supply and demand principles and seeks to constantly innovate in order to meet the demands of health system users who are “clamoring for medical miracles”104. So, even in a Canadian context, where universal health care is publicly funded and managed and private interests are kept to a minimum, the term ‘industry’ is still useful because it characterized the behavior of the specialty. Because neonatology operates and behaves within an economy of supply and demand it needs to be considered whether neonatology is both fueling its own demand, and responding to it. In part neonatology might be responding to parent’s demands and public support for rescuing small babies, in part it might be responding to practitioners’ professional need to constantly innovate ‘miracles’ and push the boundaries of viability. The ‘need’ to innovate requires ongoing investment of medical and financial resources. This, in turn, leads to increasing rates of obstetric interventions. This cyclical feedback loop is certainly characteristic of an expansionist health industry rather than benevolent healthcare.

While much research associates premature birth with maternal incompetency and social/biological deficiencies, it may also be that increasing rates of prematurity may be partly manufactured. Rising preterm birth rates may be the consequence of intercepting babies from stillbirth.

Many hospitals are establishing or expanding neonatal services in North America and elsewhere. The NICU has become “the economic engine” of most children’s hospitals, especially in the United States. Without NICUs, many hospitals would implode.  

“Pediatric departments and children’s hospitals are now financially dependent on NICU preemies,” says John Lantos, a neonatal bioethicist. Neonatology has become the “economic “lifeblood” of pediatrics”. Essentially, NICUs make children’s hospitals economically viable. “We imagine that we are working to protect premature babies because they need us, but it turns out that the preemies are also working for us.”

The growing subspecialty and expansion of NICUs stems from economic altruism. NICU’s have the highest revenue-to-expense ratio of any adult or pediatric unit in hospital based practice. In other words, more NICU beds mean that less viable subspecialties in pediatrics can be cross-subsidized and sustained by NICUs. Unsurprisingly, the number of NICU beds in American hospitals grows and will continue to grow, trumping the need for more general practitioners, new emergency departments, gerontologists, or outpatient clinics.

Gayatri Spivak might proffer an interpretation, here. Sometimes suffering occurs when the professional text needs a body, yet cannot acknowledge that need.

The Spectacle of Smallness: A History of Prematurity from the Freakshow to the NICU

Contemporary neonatology exists within a context of rapid transformation and acceleration. The goals of medicine seem to be transforming, or expanding. Today, medicine and medical progress is accompanied by a heroic ethos and a growing interest in technological exuberance and intervention, not

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110 Spivak, G. in A. Frank 1995 p. 25
the least of which are increasingly aggressive efforts to overcome the implicit errors of natural procreation, to eliminate or exorcise human difference and variation, and to stave off death itself.

The evolution of medicine and technology over the last 100 years has had a tremendous impact on the natural existence of bodies and reproduction, specifically. Coupled with the trend towards scientific medicine and modernization, momentum has grown towards more and more acute care and aggressive medical intervention during pregnancy and birth. All this is fuelled by an ethos of medical heroism and uncritical belief in the capacity of medicine to overcome all of the inherent errors and ills of natural existence. Fuelled by this heroic ethos, life and death have become fully equivocal events. The gradual hospitalization of childbirth, coupled with the advent of high-tech prenatal surveillance programs illustrates the extent to which the modernization of medicine has moved forward on the heroic promise of being able to medically and technologically improve upon our natural existence and our implicit errors. Rapid advances, the implementation of scientific research and technology continue to transform human reproduction. Some of these technologies include genomics, therapeutic cloning and embryonic stem cell therapies, gene therapy, genetic engineering, and ‘germinal choice technology’, sex selection, egg harvesting, fetal tissue transplants, among others. We continue to invent new technologies in order to intervene pregnancies and customize fetuses that are seemingly more ‘fit’ for the future. At times neonatology is in-step with this effort and at times, it seems at odds with it.

The 1890’s were credited with prominent medical innovation, discovery and cures. The discovery of tuberculosis bacillus, Pasteur’s rabies vaccine, and Behring’s diphtheria antitoxin set a rapid pace and built an astonishing amount of momentum and appetite for innovation in medicine in the

\[111\] Baker, J. (1996) p. 113
\[112\] It wasn’t until the 1870’s that the incorporation of science into medical curriculum could be found. Harvard University pioneered medical science in the 1870’s, John Hopkins University, in 1893. Technology was both a symptom and an effect of the rise of scientific medicine. See J. Baker. (1996) p.106.
1900s. The promise of medical science was irrefutable. And, as the march of medical progress gained surer footing and credibility, non-treatment of premature infants became an obsolete option. Infanticide, or deliberate non-treatment, became a betrayal of the entire drive of medical progress, generally, and of neonatal care, specifically. The neonatologist’s whole professional life became devoted to the denial of the biological leaving ritual for the premature infant. The neonatologist’s career in itself was a culminated protest against death’s agonal rattle. As treatment options were refined, so too were over-treatment and experimental options put into play. Preterm, borderline babies received (and continue to receive) unlimited medical intervention at the discretion of practitioner’s. The technological imperative and the therapeutic imperative accelerate the pace of medical progress. Heroic measures, often aggressive, experimental, and unbridled, have become the accepted and expected standard of treatment. Marginally viable babies are now born into the world under a mantra of “don’t just stand there, do something….anything”. Biological destiny is now book-shelved by a technological imperative. All this, despite the possibility that innovative technologies and therapies have not been proven safe or effective.

The evolution of neonatology is full of paradoxes, swerves and counter-intuitive turns. Neonatology is a peculiar medical subspecialty that evolved from early 19th Century French nationalism, early American sideshow freak culture, and the eugenics movement. Traces of these three unlikely influences in the evolution of neonatology are evident in contemporary attitudes and practices in hospital-based NICUs. The Paris School of Midwives played a pivotal role in the establishment of the first known special care unit for infants during the early 1800’s. French nationalism fuelled a concerted

114 Lantos, J. (2001) p. 15
115 Agonal respiration commonly referred to as ‘the death rattle’, usually signal the moment of death. Agonal respirations are associated with great pain preceding the agony of death. J. Lantos (2001) p. 9
national effort to repopulate the war-ravaged country, in the wake of the Napoleonic Wars, 1803-1815. One of the most pivotal technologies in the development of neonatal medicine that made its debut in American circus sideshows was the incubator\textsuperscript{117}, which evolved from a poultry hatchery.\textsuperscript{118} Known as the ‘Mechanical Nurse’, the incubator was first used in maternity wards throughout France to improve infant mortality rates, and in doing so; repopulate the country in the face of postwar famine and casualties.

In North America, however, infant-rescue was viewed quite differently. The rescue of premature or ill infants was often regarded with disfavor because it encouraged the survival of infants deemed ‘unfit’ by the rest of society.\textsuperscript{119} Lacking a professional home at the onset, early neonatology took a bizarre detour in its evolution as a hospital-based clinical practice in North America. Because American obstetrics was curiously resistant to the professionalization of baby-rescue, neonatology found an unlikely home in the raucous and unorthodox environment of the early-American “freak show”. For sixty years, the first North American neonatal clinical research was conducted in theatrically enhanced medical laboratories thrust into the Midway.\textsuperscript{120} The earliest incubator-baby sideshows created and satiated public intrigue with displays of human tragedy, medical theatricality, technological prowess and spectacle. The guidebook to the 1915 Panama Pacific International Exposition in San Francisco explained,

\textsuperscript{117} The introduction of one particular incubator known as the Lion Incubator in France followed a similar pattern. The Lion Incubator appeared in store-front windows and generated profits from paying customers. The Lion incubator largely benefited the affluent French population. However, poor customers could use the incubator, provided that they displayed their children to the public, for profit, usually in storefront windows.

\textsuperscript{118} The man credited for the adaptation of a chicken hatchery for the purposes of regulating the temperatures of prematurely born infants was Etienne Stephane Tarnier, a Paris doctor, as early as 1880.

\textsuperscript{119} In part, because of this sentiment, neonatology eventually found its home not in obstetrics, but American Pediatrics. The ethical debate surrounding ‘defective’ fetus still draws largely on the perception that the ‘unfit’ represent unbearable (economic, emotional, social) ‘burden’ to society and families, suggests that not much has changed in this regard.

\textsuperscript{120} Baker, Jeffery. (1996) p. 101
The appeal of the helplessness of the unconscious mites of humanity rescued and thriving in spite of adverse fate reaches alike the specialist and the careless sightseer who may learn here the particulars of nourishment, nurture and care given these incubator babies.\textsuperscript{121}

It is estimated that 80,000 premature infants were used for public display dime-show sideshows throughout North America between 1900 and 1960.\textsuperscript{122} For those born into the highly spectacular environment of the midway, “it was not clear whether being located next to the bearded lady or having to breathe the same air as the leopards of Wombwell’s menagerie represented the greatest danger”.\textsuperscript{123} Incubator-baby shows became a fixed part of the amusement enterprise and the American imaginary and they were pivotal in fuelling the public’s palate for high-tech newborn care.

Unsurprisingly, the end-result of the first series of live incubator shows in North America were not incubator wards, but more incubator side-shows\textsuperscript{124}, including the establishment of a permanent preemie exhibit in New York’s Coney Island, at Dreamland. “What had begun as a sober, scientific exhibition became a crowded show that outdrew the Congo Village, the Tyrolean Yodelers, and the sky rides.”\textsuperscript{125} The show was opened and overseen by Dr. Martin Couney, a trained physician, self-made profiteer, midway Barker and showman. Vacationers and sightseers would pay 25 cents to enter Couney’s live incubator-baby show to gape at the preemies, along with the bearded ladies, dwarves and contortionists.\textsuperscript{126} Profiteering on the heroic ethos of rescuing tiny babies from otherwise imminent peril became a lucrative business. As is the case in contemporary NICUs, there was money to be made in the exploitation of the nameless tragedy of births figuratively delivered by “storks that perhaps had made

\textsuperscript{121} Guidebook quoted in W. Silverman (1979) p. 136
\textsuperscript{122} Baker, J. (1991) p.90
\textsuperscript{123} Baker, J. (1991) p.92
\textsuperscript{125} Liebling, A.J. New Yorker. June 3, 1939: p.22
\textsuperscript{126} Lantos, J. (2001) p.13
mistakes, or flown too fast…”127 The American public, it seemed, had “an insatiable desire to gawk contemplatively at these marvelous phenomena.”128 Neonatal technology was essentially re-invented by and for an American market that proved to have an appetite for high tech medicine.

As an entrepreneurial neonatal pioneer, Martin Couney became the first person to introduce and offer specialized care for prematurely born infants in the USA. Couney is considered one of the three pioneers of American style neonatology, along with aspiring academic and clinical investigator John Zahorsky,129 and Canadian-trained physician, Julius Hess, who was pivotal in bringing neonatology into the more credible environ of hospital-based care in the 1920’s. Only after fire closed Coney Island’s live incubator-baby exhibit, did hospitals begin offering specialized care for preemies and imperiled newborns.

It is both curious and relevant that modern neonatology is the progeny of early 19th Century live exhibitions of imperiled newborns and experimental technologies such as incubators, early oxygenation, and nasal spoon feeding.130 Indeed, neonatology’s historical detour through sideshow culture represents a dramatic departure from the familiar care standards and care practices of the day. The peculiar incorporation of neonatology into early-American freakshows explains something about contemporary NICUs. The extent to which neonatology may be partly profit-driven has already been explored in some detail. But there are also cultural, attitudinal and contemporary practices that are somewhat reminiscent of neonatology’s detour ‘outside’ the boundaries of conventional medical practice. In many ways, contemporary neonatology continues to push the limits and boundaries of medical and professional

127 This quip was taken from the guidebook of San Francisco’s Panama Pacific International Exposition in 1915. The exhibit was decorated by statues of Hungarian storks, the symbolic harbinger of luck and babies, reminiscent of the Victorian era. W. Silverman (1979) p. 136n
conventions and practices. NICUs are entirely surreal environments where intensive neonatal care for premature infants is often characterized as a high-tech rollercoaster. As in the past, neonatology continues to spectacularize and debut pioneering medicine and experimental technology while fostering a culture of technological exuberance and unfettered experimentation.

A century ago, pediatrics did not exist. “Then, at the 1912 Iowa State Fair, the President of the Iowa Confess of Mothers posed this question: “If a hog is worth saving, why not a baby?” A slow transformation began. The peculiarities of the last one hundred years of evolution in neonatology and pediatrics are many. Of the many naturally occurring ‘freaks’ that once found home on the midways and in the side-shows of American carnivals and expositions, ‘preemies’ continue to seduce the imagination, provoke interest and sympathy. So-called ‘miracle babies’ and ‘miraculous births’ decorate media coverage of premature babies. Public interest hasn’t waned; it’s grown. By contrast, many of the other wondrous physiologies of side-show freaks that shared early-American midways have been medically culled or conditioned by a paradigm of extreme medical, pharmaceutical and surgical normalization. The bearded lady, the androgen, the giant, and the dog-faced boy have effectively been disappeared by advanced western medical science, their genes culled from the pool of ‘normalcy’, their bodies pared down by scalpels in normalizing or re-assignment surgeries, their gender refined by hormones, and their behaviors, chemically fine-tuned. Some exceptional gene-types have simply been de-selected. Other anomalous gene-types have been confined to the biobank. For some, their genetic

132 Rosemarie Garland-Thomson in Freakery: Cultural Spectacles of the Extraordinary Body traces the genealogy of ‘freak discourse’ in modernity. Her work commits to stories of bodies which “defy the ordinary and mock the predictable” ways that excite anxiety and disquiet history. What Garland-Thomson calls ‘the freak discourse’s genealogy’ has witnessed an important shift in the way society relates to disability. Narratives of marvelousness have become narratives of deviance. “As modernity develops in Western culture, freak discourse logs the change: the prodigious monster transforms into the pathological terata; what was once sought after as revelation becomes pursued as entertainment; what aroused awe now inspires horror; what was taken as portent shifts to a site of progress. In brief, wonder becomes error.” See Garland-Thomson (1996) p. 1-3.
profiles have been used to warrant the ‘interruption of pregnancy’ in order to ‘improve the prognoses for the fetus.\(^\text{133}\)

Enhanced medical and technological capacity, coupled with the seductive notion of overcoming bodies’ errors, has created “a culture of disappearances”\(^\text{134}\) for babies and fetuses with exceptionalities. Predatory surveillance and termination regimes underacknowledge the relationship between strategic maternal and fetal “health improvement” services, eugenics, and social hygiene. Amidst accelerating pace, eugenics finds new footholds, gaining momentum towards the realization of an increasingly ‘Perfect’ future made possible through the predation and de-selection of otherness. After a long dormancy, “the language of eugenics stirs again,” \(^\text{135}\) masquerading in the beneficence of health population improvement. Of particular significance to this thesis is the extent to which the language of eugenics stirs in the NICU.

As neonatology progresses, we find ourselves at a troubling tipping point. We’ve reached the point in medical progress where living and dying are no longer biologically determined facts. Often, in the NICU, they are fully indeterminate events that must be decided by practitioners, parents, and caregivers through some ambiguous process that results in some babies receiving aggressive and life-saving treatments, while others do not. The negotiation around what constitutes a livable life, versus an unlivable life has become a social exercise rather than a natural occurrence. “What needs to be recognized is the need for a critical review of neonatal medicine’s growing power of social control.”\(^\text{136}\)

The relationship between the eugenics movement and neonatology is a particularly significant nexus of critical inquiry. Social Darwinism has influenced and shaped specialized infant care from its

\(^{133}\) Reist, M. (2006) p. 17
earliest inception. Social Darwinism lends itself to a theory of evolutionary progress that is socially created according to the presupposition that some social groups are ‘best-suited’ to raise the evolutionary caste of society, in general. The initial resistance to child-rescue in the United States was not because baby-rescue technologies themselves were suspect, but rather, that neonatology resulted in the survival of the ‘unfit’. One physician wrote in 1900, “that it is inconsistent with the best physical development of the men and women of our nation to treat these little creatures, it being assumed that they will have impaired physical vigor and transmit this to their offspring.”137

‘Defective newborns’ continue to cause social anxiety. Today, the NICU is, ever-so-much, a strange theatre where scenes of social Darwinism play out. It’s presupposed that some babies are worth investing in and others are less less-suited to being salvaged. It may be that eugenics is actively writing the script of neonatology, in a Procrustean138 language, both cryptic and seducing. At the same time, the continued survival of so-called ‘unfit’, ‘defective’, or otherwise ‘disabled’ babies continues to self-problematize the science of baby rescue.

Neonatology has evolved in-step with the eugenic movement which swept up medicine in the early twentieth century. It was first thought that hospitals wrongly promoted the survival of persons deemed “unfit” for society. Before long, however, eugenicists argued that society should be actively involved in improving the quality of the nation’s population through sterilization, selective breeding and selective treatment practices with regards to newborns.139 Many obstetrics hospitals in the United States exercised unwritten policies of benign neglect for premature and congenitally atypical newborns.140

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138 “Procrustes, according to Greek legend, was a robber who placed all his victims upon an iron bed. If they were longer than the bed, he cut off the overhanging parts; if shorter, he stretched them until they fit the prescribed size.” See W. Silverman (1998) p. 93
Eugenic sentiment was enshrined elsewhere in policy, as well. Until the 1970’s “Ugly Laws” and Sexual Sterilization Legislation\(^{141}\) reflected a wider social intolerance towards ‘disabled’, anomalous, monstrous, extraordinary bodies.

Neonatology represents both the “extension of medical control into the domain of the newborn”\(^{142}\) and the extension of precise scientific and social control into the domain of medicine. It has become a standing metaphor for ectogenesis, technology’s answer to the uterus\(^{143}\), ‘defective’ birthing, and flawed wombs. The technological replication of the womb is a powerful and pervasive idea in medical science. This idea feeds on the idea that science can not only imitate nature, but can improve on it, if not precisely control its perfection. As the future becomes increasingly shaped by biotechnology, it ever more important to question the inception of biotechnologies, their underlying assumptions, and embedded ‘truths’, ironies and inconsistencies. Technologies of neonatology are not merely machinic innovations, therapies or hardware. Rather, they are invested with social, political and cultural meanings which eclipse the banality of their function. And, vice versa.

**Innovation, Ignorance...Progress? The Recent Past of Neonatal Intensive Care**

Hospital-based neonatology has undergone a peculiar evolution. This section focuses on how neonatology has evolved over the past 100 years, accompanied by peculiar detours, remarkable innovations, misadventures and haphazard experiments in baby rescue.

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\(^{141}\) B.C’s Sexual Sterilization Act was in effect from 1933-1973. It granted discretionary power to a three member “Board of Eugenics” who would order the sexual sterilization of an institutionalized ‘inmate’ of a public hospital or school. The Act was silently repealed in 1973, although the aftermath of compulsory and coerced sterilizations has been met with lawsuits, out-of-court settlements and redress between the province of B.C. and the victims. B.C.’s Sexual Sterilization Act can be found at [http://canadiangenocide.nativeweb.org/governmentlegislationsexualsterilization.html](http://canadiangenocide.nativeweb.org/governmentlegislationsexualsterilization.html). The Alberta Sexual Sterilization Act enabled the legal sterilization of thousands of “unfit” persons between 1928 and 1972. A 1937 amendment to the Act meant that consent was not required by “mentally defective” persons, in order for sterilizations to be mandated by “The Eugenics Board”. McWhirter and J. Weijer’s article (1969).

\(^{142}\) Baker, J. (1996) p. 70

\(^{143}\) Baker, J. (2001) p. 656
In North America, the early years of burgeoning hospital-based neonatology saw the transference of infant rescue technologies from early American midways and expositions into the professional domain of ‘scientific’ medicine (1965-1982). The new ‘hospital-based’ subspecialty was met with considerable zeal for innovation and aggressive experimentation between the 1960’s and the early 1980’s. During this time, more aggressive interventions were developed and implemented. Cautious rules were abandoned. “Parents were clamoring for medical miracles.”

During this early period of innovation, improvements in oxygenation and mechanical ventilation resulted in better outcomes for prematurely born babies. The pharmaceutical development and use of pulmonary surfactants helped to prevent the collapse of babies’ under-developed lungs. The introduction of Total Parenteral Nutrition (TPN), and the improvement of respiratory therapies such as Intermittent Positive Pressure Respiration (IPPR) and Continuous Positive Airway Pressure (CPAP) were also ‘milestones’ of neonatology’s early period of innovation. Survival rates steadily improved as a result of these innovations.

Early clinical neonatology was met with unprecedented professional enthusiasm for resuscitating babies that, without intervention, would otherwise be stillborn. In this period of early innovation (1965 to 1982), more deliberate efforts were made to rescue smaller and younger babies from apparent death. The borderline between life and death began to blur as specialists continued pushing and seeking out new limits for innovative methods and technologies of baby-rescue. As new

146 Artificial pulmonary surfactants prevent the collapse of pulmonary alveoli with each breath. Essentially, it allows the lungs to inflate easier.
147 Lantos, J. (2007) p. 33
148 Lantos, J (2007) p. 25
149 Lantos, J. (2007) pp. 31-32
151 John Lantos calls this the period of Innovation and Individualism (1965-1982), see J. Lantos (2007) p.31
methods were introduced to rescue babies from apparent death, the presence of obstetricians and aggressive obstetric interventions in the birthing room increased\textsuperscript{153}.

In the beginning, some premature and ill newborns were stillborn or allowed to die. Later, methods such as “Shultze Swingings” or the LaBordes Method of Resuscitation were introduced to stimulate reflexive breathing in some stillborn babies. For instance, “In the late 19\textsuperscript{th} Century an asphyxiated newborn might be swung overhead by the shoulder (Shultze swingings), folded like an accordion (Byrd’s method), or have its tongue grasped by forceps in an effort to stimulate the superior laryngeal nerves (LaBorde’s method),” and so trigger breathing.\textsuperscript{154} By the latter half of the twentieth century, more aggressive neonatal resuscitation methods and mechanical ventilation techniques were developed. Neonatologist and researcher, Dr. Delivoria-Papidopolus, made remarkable contributions to the improvement of assisted ventilation methodologies designed to treat Respiratory Distress Syndrome (RDS) in newborns, and especially neonates. Dr. Delivoria-Papidopilus’s research provided the background for clinical trials related to Intermittent Positive Pressure Respiration (IPPR), a method that proved successful in providing breathing support to preemies. Her initial studies were conducted on babies who had already died, in instances where all other interventions had failed. She found that she could intubate babies, give IPPR support, and that “some of the babies could actually be \textit{brought back to life} for a short period of time.”\textsuperscript{155} The use of endotracheal tubes and positive pressure ventilation to treat RDS in premature babies was undoubtedly one of the biggest ‘milestones’ of neonatal resuscitation and early clinical neonatology. Arguably, the evolution of assisted ventilation technologies and resuscitation methods resulted in better survival rates and more widespread use among babies.

One of the other pivotal moments in the evolution of neonatology, was the implementation of

\begin{footnotes}
\item[155] Lantos, J. (2008) p.25
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Total Parenteral Nutrition (TPN), complete artificial nutrition and hydration. To treat the youngest and smallest preemies, whose digestive tracts are too immature for digestion, complete artificial nutrition and hydration was administered intravenously. At the time it was introduced in NICUs to sustain the lives of the most premature babies, TPN had never been successfully used to provide complete nutrition for other patient groups: adults, youth, or children. Nourishing the baby outside of the womb presented a significant challenge to neonatologists. It was first thought of as a “holy grail” or “Gordian knot” in neonatal medicine. One advocate and pioneer of TPN said, “The prevailing dogma among clinicians in the 1960s was that feeding a patient entirely by vein was impossible. Even if it were possible, it would be impractical; even if it was practical, it would be unaffordable.”¹⁵⁶ Neonatologists proved that although TPN is imperfect, it could be both practical and possible. There is some evidence to suggest that TPN may not be wholly beneficial, however. Complications of TPN are surfacing. “In preterm infants, prolonged intravenous feeding with solutions containing aluminum is associated with impaired neurologic development.”¹⁵⁷ Other complications might include bone disease, liver and gall bladder complications, liver failure¹⁵⁸ and association with early childhood liver cancer known as hepatoblastoma¹⁵⁹.

Many medical ‘milestones’ or breakthroughs in early clinical neonatology were abetted by medical experimentation on moribund and the most liminal premature babies.¹⁶⁰ Medical breakthroughs and experimentation was enabled by the elusion of ‘ethical’ conventions and consideration for patients and parental consent processes. Cautious rules and prevailing norms in medical research were abandoned in lieu of intensive experimental treatment and the quest for the next ‘breakthrough’ in high-

¹⁵⁶ Lantos, J. (2007) p. 33
¹⁵⁷ Bishop, N., et al. (1997) p.1560
tech baby rescue. Professional exuberance stemmed from widespread ‘let’s try and see’ attitudes towards medical experimentation with fragile preemies.\textsuperscript{161} Fearing a slowing of progress in an era of therapeutic exuberance, innovation and discovery, many treatments “diffused into clinical practice largely without any formal randomized trials”\textsuperscript{162} or the establishment of safety and efficacy standards. After two decades of ethical disavowal, coupled with the rapid implementation of innovative and experimental technologies in neonatology, the consequences and unintended consequences began to reveal themselves. Unsurprisingly, the decade following neonatology’s early period of innovation were characterized by controversy, misadventure, mishap and revelations of iatrogenesis. Questions about the aggressive nature of neonatology and the unintended consequences of medically experimenting on preemies began to surface. Neonates were caught-up in a double bind between overtreatment and undertreatment. Both were controversial.

One particular baby ignited world-wide controversy and invited global scrutiny about neonatology’s growing powers. Neonatology was becoming increasingly successful at resurrecting babies. On the one hand, neonatology often subjected neonates to a regime of over treatment. On the other hand, neonatology was becoming increasingly capable of exercising selective decision-making over which babies receive the full gamut of neonatal interventions and which babies did not. In 1982, the death of a disabled newborn ‘Baby Doe’ in Bloomington, Indiana, witnessed the beginning of intergovernmental intervention into neonatal baby rescue.\textsuperscript{163} The double-bind between overtreating some and undertreating other babies became even more controversial.

‘Baby Doe’ was born with Down’s syndrome, complicated with a congenital blockage of the esophagus which meant that anything the baby swallowed would pass into his lungs. Without surgical

\textsuperscript{161} Guyer Levy, R. (2006) p. 18  
\textsuperscript{162} Lantos, J. (2007) p. 35  
\textsuperscript{163} Lantos, J. and W. Meadow (2006) p.53
correction, the condition proved fatal. His parents did not opt for routine, life-saving surgical treatment of the blockage and ‘Baby Doe’ died of starvation and pneumonia. The parents claimed that “a minimally acceptable quality of life was never present for a child suffering from such a condition”¹⁶⁴.

While the hospital filed for an override of the parent’s refusal, the court upheld the parent’s right to choose non-treatment. In response to the ‘Baby Doe’ case of 1982, then President Ronald Reagan wrote:

> A doctor testified to the presiding judge that, even with his physical problem corrected, Baby Doe would have a “non-existent” possibility for a “minimally adequate quality of life” – in other words, that retardation was the equivalent of a crime deserving the death penalty. The judge let Baby Doe starve and die, and the Indiana Supreme Court sanctioned his decision.¹⁶⁵

The event drew public and political attention to common practices in the NICU and obstetrics, generally, namely; the selective treatment of babies, infanticide and neonaticide. Was it appropriate to withhold or withdraw treatment from a premature baby? Was it appropriate to withhold or withdraw treatment from a baby who has unknown degrees of disability? What happens when the line between medical intervention and social engineering are irreversibly blurred? When untried technologies of overtreatment are available, why not over treat babies? Not surprising, the NICU became a highly politicized scene in the 1980’s as the full implications of neonatal technologies were realized and brought to the fore of public discourse.

The ethical whiplash of this single case was profound. Bang! Suddenly, there were neonatal ethics. Who had the right to determine which infants are not worth treating? Who had the legal right to starve a child deemed ‘unfit”? Who determines what constitutes an acceptable quality of life? What of the child’s civil rights? What of the physician’s oath of beneficence, to do-no-harm? The social and political ramifications of the ‘Baby Doe’ legal case were widespread and continue to haunt NICUs

¹⁶⁴ Lantos, J. and W. Meadow (2006) p. 67
¹⁶⁵ Ronald Reagan quoted in J. Lantos and W. Meadow (2006) p. 69. Ironically, the Reagan administration, aligned with the religious right, found himself well supported by advocacy groups for people with disabilities. On this issue, their interests coincided to create a unique and unusual political momentum that became manifest in the Baby Doe regulations.
In response to the Baby Doe debacle, the United States Justice Department and the Department of Health and Human Services designed a legal mechanism for intervention in medical cases that were suspect of discrimination against children or babies with disabilities. The law was designed to uphold the ‘right to life’ for children and infants with disabilities. Any organization that refused treatment or withdrew care from a disabled infant was deemed to be in violation of so-called ‘Baby Doe’ regulations and would run the risk of losing their federal funding. The federal laws were accompanied by a poster campaign, an anonymous hotline, and investigative “Baby Doe Squads’ of lawyers, administrators, and doctors. Posters went up in NICUs across the United States and investigative squads scoured intensive care nurseries to ensure that no newborns or premature babies received differential treatment as a result of suspected or known disability. State regulations created a culture of fear around non-treatment of borderline babies and created a culture of excessive aggressiveness around infant resuscitation and treatment. Undoubtedly, state intervention and federal regulations played an important role in raising expectations for the resuscitation and treatment of more younger and smaller infants than ever before. Federal regulations made it very clear - no baby was to be denied access to burgeoning, experimental medical technologies.

The Baby Doe regulations proved unenforceable and were hugely unfavorable. After eighteen months the laws were struck down by the U.S. Supreme Court. The legislation, however, has had a lasting impact on how sick and premature babies are clinically treated and how they have become

167 The regulations were widely opposed by the American Academy of Pediatrics and hospital administrations; see. R. Levy Guyer (2006) p. 92. There was also a widespread outcry from opponents of big government, the mainstream media and the general public who, interestingly, was very concerned about the costs of caring for saving children, especially the costs associated with children who unfairly ‘burden’ the public purse with their disability, should they survive aggressive interventions; see J. Lantos and W. Meadow (2006) p. 71
entitled recipients of the most aggressive interventions on the market. Today, NICUs are still more apt to aggressively treat babies than they are to offer minimal treatments, ‘comfort care’, or let nature take course.

The legacy of “Baby Doe” continues to tease the ethical question of ‘entitlement’ or, ‘who’ should receive the benefit (and burdens) of aggressive medical interventions. Ultimately, Baby Doe legislation attempted to safeguard imperiled newborns and neonates from selective treatment and culling practices, neglectful under-treatment and discrimination in the NICU. Ironically, the legislation promoted and sanctioned unfettered use of highly aggressive, untried, experimental, and often iatrogenic treatments and interventions. What Baby Doe legislation demonstrates about neonatology is simply that neonates are born into a catch-22; subject to both strategic neglectful under-treatment and the perils of abusive or untried over-treatment. In other words, the neonate exists in a politically unenforceable double-bind.

After the Baby Doe regulations were nullified by the U.S. Supreme Court, the federal government, the American Academy of Pediatrics, and advocates of the disabled worked together to create a set of criteria for guiding treatment and nontreatment decisions for babies. This resulted in the amendment of the Child Abuse and Treatment Act, making it permissible to withhold or withdraw life-sustaining treatment from babies only if the baby met some very subjective criteria;

1. The infant is chronically and irreversibly comatose, or

2. The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant, or

3. The provision of such treatment would be virtually futile in terms of the survival of the infant
and the treatment itself under such circumstances would be inhumane.\textsuperscript{168}

Interpreting the Child Abuse and Treatment Act’s criteria for withholding or withdrawing life-sustaining medical has become a highly subjective, academic exercise. Ultimately, determining medical futility, deciding non-treatment and withholding life-sustaining treatment have been relegated to the interpretive discretion of health care professionals and their overseeing bodies. There remains very little that is binding or enforceable under the amended Child Abuse and Treatment Act. There is also an underlying assumption made in the Act that treatment, nontreatment decision take place in a clinical context where patient prognoses and outcomes are clear-cut and known. The regulations imply “a level of medical knowledge about outcomes that was largely absent from the clinical practice of neonatology.”\textsuperscript{169} As it turns out, pediatricians and neonatologists are both inaccurate and pessimistic about knowing, predicting, or perceiving the outcomes of marginally viable babies. They routinely overestimate morbidity, mortality and the costs of caring for extremely premature babies.\textsuperscript{170} Outcome studies are shadowed with uncertainty. In light of widespread prognostic uncertainty in neonatology, establishing a concrete measure for determining instances of medical futility is futile in and of itself. Arguably, non-treatment decisions amount to playing roulette amongst premature babies.

Another example of how policy influences the aggressive treatment of premature babies is the 2002, Born Alive Infants Protection Act which passed unanimously by the United States Congress. The Act is subtly reminiscent of Baby Doe Regulations of the 1980’s. The Born Alive Infants Protection Act [H.R. 2175] asserts the legal status of “any infant member of the species homo sapiens who is born alive

\textsuperscript{169} Lantos, J. and W. Meadow (2006) p.75
\textsuperscript{170} Lantos, J. and W. Meadow (2006) p. 75
at any stage of development”. The Act extends legal protection to any infant born alive, meaning:

[T]he complete expulsion or extraction from his or her mother of that member, at any stage of development, who after such expulsion or extraction breathes or has a beating heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, regardless of whether the umbilical cord has been cut.

Baby Doe Regulations and the Born Alive Infants Protection Act provide an explicit legal guarantee for infants born at any stage of development, which pre-empts decision-making at the beginning of life. However, the broader policy context around viability and the assertion of fetal and infant rights is quite varied: rapid technological advances and desire for ‘progress’ create a vacuum of varied hospital-based protocols, inconsistent policies, policy voids and classificatory confusion between hospitals, regions and countries that offer neonatal intensive care. “Neonatal intensive care is a relatively new and constantly changing specialty. The rapid rate of change has caused a variation in policies from hospital to hospital as well as in people’s perceptions of who a preemie is and of what intensive care means.” According to Gayle Whittier, “appeals to the future and technological progress tend to displace the actual patient in the here and now and replace the body with the more abstract notion of ‘progress.’”

Canada is one of a few countries that do not currently have explicit policy relating to the determination of personhood, viability, or the extension of rights to infants and/or fetuses. As such, determinations of viability, personhood and fetal/infant rights are left to the annals of bed-side

171 Italics added. See the Born-Alive Infants Protection Act of 2002. Available at: http://thomas.loc.gov/cgi-bin/query/D?c107:5:./temp/~c107qE0gUl::
prognostication and professional self-regulation of neonatal intensive care, common law and the Criminal Code of Canada. The federal government’s attempts to regulate assisted human reproduction and technologies are caught up in a jurisdictional dispute between provincial and federal regulatory bodies. Initiated in October 1989, Canada’s Royal Commission on New Reproductive Technologies aimed to explore “current and potential medical and scientific developments related to new reproductive technologies” and to consider their “social, ethical, health, research, legal and economic implications.” Over a decade passed before such a regulatory mechanism received Royal Assent. By design, the Assisted Human Reproductive Act (AHRA) of 2004 aimed to prohibit and control a narrow and specific array of technologies and practices outlined by the Royal Commission.

Canada’s AHRA has been hotly contested. In 2008, following an appeal by the Government of Quebec that the provisions of the Act fall under provincial jurisdiction, the Quebec Court of Appeal concluded that the AHRA is unconstitutional and that the provisions of the ACT fall outside of federal powers. While the Government of Canada appeals to the Supreme Court of Canada regarding the constitutionality of federal regulation of assistive human reproductive technologies, the Act remains in force, although the Assisted Human Reproduction Agency and Health Canada has delayed publication of all subsequent publication of proposed and draft regulations around assistive human reproduction. Regardless of its constitutional validity, as it stands, the AHRA has limited relevance or impact on the complex issues that arise in neonatal critical care. If deemed constitutionally valid, the AHRA and the AHR Agency may play a role in future policy development relevant to neonatal intensive care and

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decision-making for babies born on the borderline. If deemed constitutionally valid, lagging policy development will remain a provincial matter.

Policy and common law seemingly sanction ‘let’s try and see’ attitudes which propels high-tech and untried therapies: both in human reproductive medicine and neonatology. Indeed, the implications of regulative policies and policy voids are profound. Because all prematurely born babies are now legally entitled to receive aggressive interventions, they do. More babies are resuscitated and receive extra heroic interventions than ever before. It’s ironic that the American public and medical community was seemingly pitted ‘against’ the resuscitation of weak, small, or premature babies in the early 20th Century. 100 years later, the ironic reversal has happened. Now, according to federal regulations, all babies born at the borderline are entitled to resurrection – despite considerable uncertainty about long-term outcomes and the safety and efficacy of available treatments.

Policy offers a legal guarantee for infants born at any stage of development, which pre-empts decision making at the beginning of life. Policy, again, seemingly sanctions the aggressive ‘let’s try and see’ attitude which propels high-tech and untried therapies: both in human reproductive medicine and neonatology. Indeed, the implication of the Born Alive Act is profound. Because all prematurely born babies are now legally entitled to receive aggressive interventions, they do. More babies are resuscitated and receive extra heroic interventions than ever before. It’s ironic that the American public and medical community was seemingly pitted ‘against’ the resuscitation of weak, small, or premature babies in the early 20th Century. 100 years later, the ironic reversal is happened. Now, according to federal regulations, all babies born at the borderline are entitled to resurrection – despite considerable uncertainty about long-term outcomes and the safety and efficacy of available treatments.

Aggressive measures often create a sequelae of medical misadventure, iatrogenesis, and ethical friction. It’s a complex and ironic feedback loop: policy extends legal ‘rights’ for imperiled newborns to
become privileged beneficiaries of high-tech neonatal care and innovative medical interventions. The unintended consequences of innovative therapies surface in the living bodies of neonatal ‘survivors’. Policy turns 180 degrees, asserting the right of doctors to declare ‘futility’ and pursue a course of actively withholding treatment from neonates they suspect will have a ‘poor’ outcome. And the cycle goes on as society grapples with the consequences of overtreatment and undertreatment. A double-bind asserts itself - to under-treat babies is negligent, to over-treat babies is disastrous.

What does the aftermath of innovation and experimentation look like? Following decades of clinical innovations and experimentation in neonatology, the unintended consequences of clinical experimentation and innovation in neonatology began to surface. The full implications of playing therapeutic roulette in the nursery have yet to be fully understood. Neonatology’s experimental exuberance coupled with a propensity for iatrogenic outcomes are evident in at least four different (ongoing) clinical experiments: oxygenation, the use of potent steroids to treat lung disease, the use of anticonvulsant drugs to control neonatal seizure and pain management therapies. Complications that arise from prolonged artificial nutrition and hydration (TPN) have been mentioned elsewhere.

It may be inaccurate to call many innovations in neonatology distinct “milestones” as many of them carry with them the baggage of iatrogenesis, medical mishap and adverse events. Consider the rash of neonatal blindness which swept through NICUs in the 1940s and 1950’s. As result of quickly standardized oxygenation experiments in neonatology many premature babies became blind. Infant oxygenation was a seemingly harmless and uncomplicated treatment designed to ease breathing in the extremely premature infant. Faced with babies starved for air, nurses and doctors began to routinely administer high-dose oxygen to ease respiration and improve the incidence of respiratory failure and chronic lung disease to which many preemies are susceptible. All gasses become toxic under the right conditions, however. The end result of solving one problem (respiratory distress) created other
problems (blindness and developmental disorders). Overly high oxygen, low oxygen and fluctuating oxygen saturation levels can cause oxygen toxicity, which can lead to Retinopathy of Prematurity (ROP), blindness, possible neurological impairment, or even death in preemies. The unintended iatrogenic consequence of experimentation with oxygen saturation among preemies still haunts neonatologists.

Researchers estimate that by the 1950s, over eight thousand preemies in the United States grew up blind as a result of Retinopathy of Prematurity.\textsuperscript{177} Today, neonates continue to survive the NICU with severe Retinopathy of Prematurity leading to blindness and neurological impairment as a result of oxygen toxicity. The optimum dose of oxygen that is safe and effective for preemies remains uncertain.\textsuperscript{178} Nearly sixty years of inconclusive trials surrounding oxygenation have passed and neonatologists still don’t really know what concentration of oxygen is safe, let alone optimal. Today it is widely accepted that improper oxygenation resulted in an iatrogenic rash of neonatal blindness and many cases of neurological impairment.

Experimentation with oxygen saturation levels is certainly not the only therapy to be found toxic to premature infants. The routine administration of steroids to premature babies in the 1980’s and 1990’s has been linked to significant neurological impairment among neonatal survivors. The offlabel administration of the steroid dexamethasone became widespread, routinized treatment for ventilated babies because it was often credited with reducing the number of days babies spent on ventilators. So, “Neonatologists jumped on the dexamethasone bandwagon with both feet and without thinking through

\textsuperscript{178} Lantos, J. (2007) p. 20-21
the potential complications”. Both the Canadian Pediatric Society and the American Academy of Pediatrics Committee on the Fetus have since directly linked routine steroid administration with:

[F]urther reduced size of the premature brain and increased rates of cerebral palsy, cognitive deficits, and severe retinopathy. Two large randomized controlled trials of postnatal steroids were halted prematurely because of serious short term complications such as intestinal perforations, growth retardation, periventricular leukomalacia [neurological impairment], hyperglycemia, hypertension, and infection. For two decades, neonatal postnatal corticoid steroids (NPCS) such as dexamethasone were routinely delivered to low-birth-weight, ventilated neonates across Canada and the United States, despite inadequate clinical trials which prove the safety and efficacy of NPCSs in treating lung damage and disease caused by prolonged ventilation. After two decades, the undeniable, unintended consequences began to surface. By 2002, the Canadian Pediatric Society issued a recommendation that the use of NPCSs should be limited to clinical trials which require the participation of fully informed and consenting parents. While concerns about the use of steroids to treat lung disease and expedite lung development for neonates have been mounting for over a decade, the most potent corticosteroid, dexamethasone, continues to appear on patient records who are not participating in clinical trials, where high-risk information was not provided to parents or proxy decision-makers, and where consent was not granted. Neonatology has a bad habit of keeping new and innovative techniques and therapies outside of the formalities of randomized, controlled clinical trials that aim to establish whether a given drug or therapy is safe and effective. When a drug exploration appears favourable, the ‘innovation’ is

181 Harrison, H. (2002) p. 113
182 Personal Health Records. Neonatal Follow-up Summary (Januar 15, 2004)
183 Noguchi KK (2008) p. 1582
quickly baptised as ‘standard practice’.\textsuperscript{184}

Although the steroid, dexamethasone, was commonly used to treat chronic lung disease (Bronchopulmonary Dysplasia (BPD)) in neonates, it has never been licensed for use\textsuperscript{185}. While the drug is successful in encouraging rapid extubation of infants who are dependent on assisted respiration, it has not undergone trials for safety or efficacy in neonatal patient groups. Interestingly, over 90\% of neonates will be prescribed at least one unlicensed or off label drug in the course of their hospitalization.\textsuperscript{186} Very few pharmaceuticals used in both emergency and routine treatment have been adequately tested for efficacy and safety on neonatal patients.\textsuperscript{187} Dr. Keith Barrington, Chair of the Canadian Pediatric Society estimates that the widespread use of post-natal cortico-steroids in NICUs across Canada and the United States will result in more than 1000 extra cases of neurodevelopment impairment and more than 1600 extra cases of cerebral palsy per year.\textsuperscript{188} The cumulative iatrogenic impact of two decades of prescribing dexamethasone to preemies is not yet known.\textsuperscript{189} The combined effects of therapeutic exuberance in prescribing catastrophic “bandwagon” pharmaceuticals to neonatal patients and failing to establish a rigorous patient-safety culture will continue to haunt the evolution of neonatology.

Some neonatologists continue to resist the joint recommendations of the American Academy of Pediatrics Committee on the Fetus and Newborn (AAPCFN) and the Canadian Pediatric Society (CPS). Responses to the non-binding joint-recommendations of the CPS and AAPCFN, suggest that dexamethasone, among other steroids with “detrimental side effects” continue to be “routinely” used,

\textsuperscript{184} Silverman, W. (1998) p. 8
\textsuperscript{185} Ref. Table 2 in I. Choonara, et al. (1999) p. F143
\textsuperscript{186} quoted in D.J. Manning (2005) p.266
\textsuperscript{187} Choonara, I. et al. (1999) p. 143f
\textsuperscript{188} Barrington, K. in H. Harrison (2002) p. 111
\textsuperscript{189} Harrison, H. (2001) pp. 57-59
off-label. In clinical practice some neonatologists believe these recommendations represent another extreme:

We [neonatologists] may cause more harm by not administering steroids than we presently do. This leads me to my major disagreement with the recommendations—parental consent before use. I do not feel that we should abdicate our decision-making responsibilities to the families for these issues. How many other medications do we use in the neonatal intensive care unit that have been subjected to far less scrutiny than glucocorticoids that also have detrimental side effects? It’s a slippery slope—today, dexamethasone; tomorrow, ampicillin\textsuperscript{190}? The use of steroids is not a decision that should require parental consent.\textsuperscript{191}

The off-label use of dexamethasone to treat bronchopulmonary dysplasia (chronic lung disease) in neonates illustrates the deleterious effects of rampant off-label prescribing practices and the failure of the industry and policy-makers to truly commit to better pharmaceutical practice for neonates in intensive care. Amidst a drought of knowledge about the safety and efficacy of many drug therapies in neonatology, roulette style drug management ensues, further magnifying the absence of knowledge that should guide practitioners and parents in decision-making. Despite the CPS recommendations for subjecting dexamethasone to clinical trials, including a process of formalizing and obtaining informed consent, there is evidence to suggest widely varying degrees of responsiveness to recommendations that would curtail the use of drugs that are associated with iatrogenic outcomes.

Another example of pharmaceutical experimentation and the use of off-label and unlicensed pharmaceuticals in neonatal intensive care is the use of pharmaceutical anti-convulsants to control seizure activity. The most conventional anti-epileptic drugs used in neonates, phenobarbital and phenytoin, have been used since 1914 as anticonvulsants in adult populations. Over the years, their use

\textsuperscript{190} A commonly prescribed antibiotic.  
\textsuperscript{191} Burchfield, D. (2003) pp. 221-222
has been extrapolated (not indicated through clinical trials) into other patient groups and clinical practice, including the treatment of neonatal seizures in patients with underlying neurological complications and/or neonates at high risk for neurological complications. The off label and unlicensed use of these conventional drugs, although commonly prescribed to adults, is not clinically justified by research suggesting that they are effective or even safe to use in the treatment of neonatal patients. In fact the treatment of neonatal seizures with off-label anticonvulsants is very poorly indicated and research has demonstrated a proven lack of efficiency.\textsuperscript{192} 2005 trials suggest that “despite aggressive treatment with phenobarbital/phenytoin, clinical and electrical control of neonatal seizures was unsatisfactory (46.8%).”\textsuperscript{193} Despite the lack of efficacy of phenobarbital and phenytoin in treating neonatal seizures, the continued use of off label phenobarbital and phenytoin indicates that, after all these years, neonatology, “still loves what doesn’t work.”\textsuperscript{194} One researcher remarked that “in the treatment of neonatal seizures, the chasm between what we know from the bench and what we do in routine bedside practice is wide.”\textsuperscript{195} Undoubtedly this is a common trope in neonatology. There is a notable schism between what is known and what is practiced.

Another example of pharmaceutical experimentation and the use of off-label and unlicenced pharmaceuticals in neonatal intensive care is the use of pharmaceutical anti-convultants to control seizure activity in neonates. The most conventional anti-epileptic drugs used in neonates, phenobarbital and phenytoin have been used since 1914 as anticonvulsants in adult populations. Over the years, their use has been extrapolated (not indicated through clinical trials) into other patient groups and clinical practice, including the treatment of neonatal seizures in patients with underlying neurological

\textsuperscript{192} Painter, M. and R. Sankar (2005) p. 776
\textsuperscript{193} Castro Conde, J.R., et al. (2005) p. 879
\textsuperscript{194} Painter, M. and R. Sankar (2005) p. 776
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There is another trend guiding treatment decisions for neonatal seizures in North American NICUs - the off-label use of new anticonvulsant drugs to treat neonatal patient populations. “Pediatric neurologists are recommending treatment of neonatal seizures with newer agents, despite a lack of info about their safety or efficacy in this population.”\textsuperscript{200} The two most widely used “new” antiepileptic drugs being used to treat neonatal seizures are topiramate and levetiracetam. Despite their widespread usage, there is a disturbing lack of information available regarding the effects of these drugs on brain development, on the safe use of these drugs in child, pediatric, or neonatal patient groups, appropriate dosing, or the administration of these drugs in alternate formulations, namely intravenous

\textsuperscript{196} Painter, M. and R. Sankar (2005) p.776
\textsuperscript{197} Castro, Conde, J.R., et al. (2005) p. 879
\textsuperscript{198} Painter, M. and R. Sankar (2005) p. 776
\textsuperscript{199} Painter, M. and R. Sankar (2005) p. 776
\textsuperscript{200} Ferriero, D. and F. Silverstein (2008) p.77
Because of this research deficit, pediatric neurologists can only extrapolate from their clinical experiences in treating adult or older children with newer antiepileptic drugs. This should be a cause for concern for the baby-rescue industry. “There is a paucity of data regarding the pharmacokinetics of many drugs and interactions among medications in neonates, and “off-label” drug use is very common in this age group.” Continued experimentation in aggressive pharmacotherapies among neonates will undoubtedly have consequences, and unintended consequences, and iatrogenic consequences. This trend is as much a part of the evolution of neonatology over the past 100 years.

Another aspect of neonatology that haunts the evolution of baby-rescue, is the underacknowledgement of neonatal pain. The promise of medical miracles often acts as a social anesthesia to the implicit harm and implicit pain caused by technologies, experimentation, and therapeutic mishaps in the NICU. Often enough, long after discharge, parents of neonates discover that the life-saving surgeries were performed on their children without adequate pain relief or even anesthesia. Up until recently, thoracotomy and patent ductus ligation were routinely performed surgeries on neonatal patients, undertaken without analgesic or anesthetic. In lieu of pain-relief, oxygen and muscle paralyzing agents were administered to ensure the compliance of the patient’s body throughout major and minor surgeries. Tranquilizers such as Pavulon were considered safer than analgesics, opiates and narcotics. However, tranquilizers and paralytic agents merely create the illusion of a pain management strategy during invasive procedures and surgeries. They do not relieve the body of pain. Rather, they simply immobilize the body’s muscles and prevent the body from writhing during the physical, emotional, and psychological experience of pain.

203 Open chest surgery.
205 Pavulon is a commonly prescribed paralytic agent used to paralyze neonates.
Until recently, it was widely accepted in neonatology that premature babies are too neurologically immature to feel pain. Presumably, the nontreatment of pain among premature infants harkens back to the mid-nineteenth century approach to pain-management for infants and children. Henry Bigelow and Martin Pernick (among others) maintained that “The new technique [the use of anesthetics] is unnecessary for infants, because they lack the anticipation and remembrance of suffering.” It was commonly held that infants, while undergoing surgery, could “insensibly sleep” and that the capacity to experience pain was not established in infants because “like lower species…babies lack the mental capacity to suffer.” An accepted surgical protocol involving infants, as reported in 1854, indicated that “the child patient was rolled firmly in a sheet, as a substitute for ether.” By the 1980’s, child patients were immobilized not with sheets, but a thick veil of paralytics, namely, Pavulon. Apparently, this is what 100 years of medical progress means. We have developed a pharmaceutical alternative to the tightly rolled bed sheet method of restraining infants in pediatric operating theatres. The opinion that premature infants are too immature to feel pain resulted in the under acknowledgement of neonatal pain, the widespread justification of nontreatment of pain in clinical practice and surgical procedures and a significant lack of understanding about the health sequelae associated with untreated neonatal pain.

The International Association for the Study of Pain (IASP) has taken a leading role in exposing the neglectful under treatment of pain among neonates:

Until recent years, infants typically received inadequate analgesia for a range of medical procedures and even major surgery. These practices were justified in part on the basis of fears regarding risks and complications of analgesics in infants. In addition, there were widely held

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views that neonates do not experience pain as suffering, that they do not remember pain, or that, if pain is experienced as suffering, it produces no lasting consequences.\textsuperscript{210}

New research, conducted by the University of British Columbia’s Centre for Community Child Health Research, among others\textsuperscript{211}, have found that pain is real and measurable in neonatal babies and that neonatal pain is directly related to the long-term, possibly lifelong alteration of the stress hormone system. UBC researcher Ruth Grunau (et. al.) found that “Preterm infants born less than 29 weeks of pregnancy, as a group, showed higher levels of cortisol than expected.”\textsuperscript{212} Essentially, these research findings help to demonstrate that pain-related stress experiences in the NICU can effectively “reset” the stress management system for children born extremely premature.\textsuperscript{213} Preemies, according to the study, had a diminished capacity to maintain appropriate levels of cortisol (the main stress hormone) during day to day activities. The under acknowledgement of pain, coupled with the under usage of effective pain management can have lifelong consequences for neonates. Heightened cortisol levels in the body mean that usual, day to day childhood routines may be overshadowed by feelings of anxiety and stress.

After a decade of playing medical roulette among preemies, the unintended consequences of therapeutic exuberance are emerging. While innovation, experimentation and therapeutic exuberance are still hallmarks of neonatology today, a subtle shift has occurred. Facing growing concerns about the number of iatrogenic outcomes in its recent history, data has become the Holy Grail of neonatology. Like no other time in its evolution, researchers are working to establish a more reputable ‘evidence-

\textsuperscript{210} Goldschneider, K. R. (1998) p.1
\textsuperscript{211} Anand, K. and P. Hickey (1992) and M. Rogers (1992)
\textsuperscript{212} Grunau, R. (2006)
\textsuperscript{213} In light of new research findings relating to pain and pain management in preterm infants undergoing intensive care, the industry is beginning to incorporate individualized pain management programs for neonates. Pain management programs include: training, stress observation, pain assessments, and administration of analgesic pain medications, as well as pain prevention and non-pharmacological pain prevention techniques. See American Academy of Pediatrics: Committee on Fetus and Newborn Committee and Canadian Pediatric Society: Fetus and Newborn Committee. “Prevention and Management of Pain and Stress in the Neonate” in Pediatrics (February 2000).
base’ worthy of guiding the neonatal subspecialty and informing policy. Large-scale, multi-center outcome studies attempt to mitigate the dearth of known long-term outcomes for premature babies who receive intensive care. The concerted drive to create an evidence base for neonatology demarcates a new phase in the evolution of neonatology. Multi-center databases, research projects, and neonatal networks attempt to consolidate and make sense of the sudden surplus of clinical data being produced by newly implemented technologies. As the cybernetic pace of innovation unfolds and the implementation of always-newer techniques and technologies accelerates in the NICU, it remains to be seen whether the construction of an evidence-base will keep pace with an always-changing industry, or if ‘evidence-based practice’ represents a moving target in an end-game of therapeutic roulette.

The evolution of clinical innovation in neonatal medicine is frightening and accompanied with considerable hubris. Medical adventures and innovations often end in misadventures. Clinical innovation in neonatology has unfolded with irrational and tragic exuberance, serendipity, scientific skill, failure, ruin, success and luck. “The early history of the [technology] poses problems for those who would see medical technology as evolving along a line of progress.”214 More often than not, ‘successful’ innovations have been fictionalized into more orderly, often linear narratives of discovery and quantifiable ‘progress’.215 “The [innovations] that succeed are remembered and create a sanitized version of the history of medical progress.”216 Failed innovations, medical mishaps, and iatrogenesis offer different accounts of neonatology’s peculiar evolution. The most haunting aspect of contemporary neonatal practice is that the techniques being developed for neonatology are not definitively effective or not effective. Rather, they are somewhere in-between. That is, controversy arises when rescue techniques are only partially effective, “saving life, but not curing the diseases to

215 Lantos, J. (2007) p. 18
216 Lantos, J. (2007) p. 20
which premature babies [are] heirs.\textsuperscript{217} It could be more directly stated that rescue techniques are only partially effective: saving life, but causing disability. Ironically, for ‘partially successful’ neonates, those that survive with disability are awkwardly situated somewhere in-between definitive progress and outright catastrophe.

Curiously, throughout its evolution, the pattern of baby-rescue has been interrupted by the randomness of disability. Disability has always walked hand in hand with neonatology, from the midway into the sterile world of the contemporary NICU. Neonatal follow-up studies suggest that half of extremely low birth weight and early gestation babies are diagnosed with a disability serious enough to be detected before the age of two or three.\textsuperscript{218} Many diagnoses don’t present or can’t be reliably diagnosed until mid-childhood, meaning that the occurrence of disability is actually higher than the follow-up studies maintain. Practitioners and bioethicists continue to struggle with the idea that neonatology is only ‘partially successful’ in salvaging babies. Pediatrician and bioethicist John Lantos perceives that “the blessings of neonatology might be so tainted with curses that it would be hubris to seek them.”\textsuperscript{219} Arguably, neonatology and disability are so intimately bound, that the technologies of neonatology may be actively lowering rates of infant mortality and morbidity, and manufacturing disability itself. The evolution of contemporary neonatology cannot be told apart from the counter-narratives of disability, the mishaps and the misadventures it creates.

This chapter provides an extensive exploration of neonatology over the last 100 years of its evolution as a clinical practice. The evolution of neonatology is peculiar in a number of ways. It’s certainly curious that while pregnancies have never been more micro-managed, intervened and

\textsuperscript{217} Lantos, J. (2007) p. 37
\textsuperscript{219} Lantos, J. (2007) p. 37
surveyed, that premature birth rates continue to rise. It’s also curious that contemporary neonatology detoured
Miracles, Metaphors and Magic:  
The Ambiguous Codes of the NICU

When a neonatologist is faced with two bluish feet protruding from the vagina of a woman who is approximately twenty-five weeks pregnant, they must differentiate this emergent person from the certitude of the past and an indefinite future. The impossibly small bluish body that emerges from the mother’s womb, extremely premature, is the fetus of ambiguity. Is this life?

This chapter sets out to do four things. First, it explores the ambiguous spectacle and theatre of preterm birth and the Neonatal Intensive Care Unit (NICU). Second, it considers what metaphorical codes can explain about neonates and neonatal medicine. Third, it examines neonatology as part of a broader baby-making enterprise that is rewriting the rules of human reproduction. Fourth, the extent that desires for normalcy is entwined with efforts to ‘fix’ or ‘improve pregnancy’ are considered. The specter of eugenics is raised. In particular, the dominance of the medical model of disability in neonatal medicine falls under the microscope. Finally, the latter part of the chapter explores the force and impacts of miracle rhetoric and the media’s role in fuelling public appetite for evermore aggressive interventions at birth and during pregnancy. The impacts of social discomfort and stigmatization of disability are exposed throughout the chapter; metaphorically, in the NICU, in ART, and in the media. All this builds towards the recognition of a need. Perhaps a new conception of disability is needed in order to decouple disability from a purely medical model, from stigmas, from eugenic programs, and from our most intimate fears and desires.

221 Lantos, J. (2001) p. 8
The NICU Experience: Raw Nerves, Ethical Ataxia and Intense Ambiguity

A mother says:

They tell me that they will place my son upon my chest so that he may go peacefully in his first few moments of his life. They tell me the resuscitation limit is only 15 minutes long.

Sometimes, they don’t “go”. It is rarely ‘peaceful’. It is something far more ambiguous than that. Without aggressive intervention, the life of an extremely premature baby is biologically impossible. Aggressive medical intervention is deployed. There may not be pulse, but one can be conjured from the body. There may not be spontaneous breath, but that too, can be artificially simulated through intubation and mechanical ventilation. A thin plastic tube is inserted in the baby’s windpipe, adrenaline administered, chest compressions initiated (100 per minute). Paper-thin lungs are inflated by the repetitive manual squeeze of an airbag in the grip of a technician’s hand. With the insertion of a plastic tube only one twentieth of an inch in diameter, and the chemical excitation of the body by adrenaline and other chemicals, technology wills the miniature body away from its biological leaving ritual. Artificial nutrition and hydration sustains life outside the womb. It is in this prolonged moment that technology interrupts death’s agonal rattle, the prose of Thanatos. It is in this counter-intuitive moment where Thanatos is silenced that medical progress seemingly leaps forward. It is in this way that each preemie, is, in a sense, an impossibly small Lazarus, resurrected by a secular technological will.

By splicing biological, technological, legal, and medical conditions of possibility, life can be manufactured and death can be thwarted. The process is unimaginably ambiguous. The extremely prematurely born hover in this equivocal vertigo. At the same time that they are mechanically tempted

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#footnotes

222 Conn, N. in “little Man” (2006)

223 Thanatos is figured in Greek and Roman Mythology. He is the personification of death and mortality. Thanatos is also post-Freudian psychoanalytic term which refers to the death instinct or death drive, “an urge inherent in all organic life to restore an earlier state of things”. See S. Freud. *Beyond the Pleasure Principle* (1920) p.36
into living, they overcome death. Neonatology thrives on the “triumphalist temptation to slash and suture our way to eternal life”\textsuperscript{224}. The extremely prematurely born exist somewhere beyond the heaped wreckage of a biological destiny, in the wake of an emergent future that is technologically willed by the mounting storm of medical progress.\textsuperscript{225} Why conceptualize the progress of medicine as a storm? The triad of medicine, science, and technology must reckon with the looming failure of a paradigm that has been shaped and driven by an overarching summons to perfection. It may be that we are already living the wake of this storm, or even its aftermath. This failure is becoming so feasible that it can no longer be denied. Medical progress must reckon with its own fault-lines and failures and the possibility that progress may involve the simultaneous mastery of nature and the retrogression of society.\textsuperscript{226} The aggressive technologies and medical heroism that compel the prematurely born into living belie these two tendencies of modern medicine. Modern medicine propels \textbf{both} the aggressive and possible mastery of nature \textbf{and} the retrogression of society into accumulating illusive powers over social hygiene. As our technological capacity leaps forward, so too do our growing power over social control.

It may be that in neonatology, we can behold something that is often very difficult to articulate: that destiny is unfolding and being shaped by forces that are \textbf{both} heroic \textbf{and} eugenic, simultaneously progressive and retrogressive.

For some, the NICU is a place where miracles are forged in the furnace of a future defined by advanced medical science and progress beyond limitation. For others, the NICU is a grisly scene where certain forms of “human” are discontinued. In many regards it is both. The NICU is a world defined by wildly unexpected and macabre events\textsuperscript{227}. “There is probably no eerier place in a hospital than the

\textsuperscript{224} Ramsey, P. quoted in W. Silverman (1998) p.167
\textsuperscript{225} Benjamin, W. (1968) pp.257-258
\textsuperscript{226} Benjamin, W. (1968) p.259
\textsuperscript{227} Conn, N. in “Little Man” (2006)
NICU. One enters…prepared to see tiny babies. But the babies are unimaginably tiny. They are magical.” And, they evoke discomfort.

Enter the world known as the NICU:

*Four surgeries.*
*Two codes.*
*Chest compressions.*
*Hundreds of baggings.*
*Collapsed lungs.*
*Six different ventilators, oscillators and jets.*
*Hundreds of suctionings from the lungs.*
*Needles in every conceivable vein.*
*Heel sticks until the foot looks like swollen strawberries.*
*Excreting feces from the stomach.*
*Eight centimeters cut from the bowel.*
*Thirty blood transfusions – platelet infusions.*
*Countless re-intubations and repeated catheterizations.*
*Four kidney failures.*
*A spinal tap…* Sounds like a car accident casualty.
*Triage at the sight of battle.*
*An unexpected victim of terrorist catastrophe.*

But it is none of those things.

*This is my son's first month of life.* – Nicole Conn

This is the unthinkable first month of life for many micro-preemies. Each baby in the ward is…

…connected to a variety of machines and monitors – mechanical ventilators, cardiac monitors, intravenous infusion pumps, intraarterial pressure gauges, temperature sensors. Officious nurses hover[ing] over the bassinets, occasionally picking up or turning the babies, but mostly, it seem[s], watching the monitors, keeping the buzzers from buzzing and the beepers from beeping, measuring medications in tiny syringes and injecting the needles…

Each impossibly small body is environmentally micro-controlled within a plexi-glass incubator. Each bodily system is tapped into by some technology or another; pharmacokinetic, pharmacological,

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228 Lantos, J. (2001) p. 28
230 Lantos, J. (2001) p. 25
technological, biomechanical. Each system is tapped into, functionally over-ridden, and screened for information. Each data display is alarmed for system failure, mechanical or biological, the machines are ambivalent. It is a cyborg mise en scene, a tenuously articulated fusion of fetal flesh and synthesized systems.

Sixty-five breaths per minute are administered by a Drager 2000 Ventilator. A pump pushes breast milk down her throat, through a tube that goes into her belly. Before long, her tummy will become inflamed and the tissues of her bowels will begin to necrotize\textsuperscript{231}. Sepsis sets in. They’ll stop ‘feeding’ her the milk that I mechanically pump through blistering nipples four times a day. They’ll start TPN – total parenteral nutrition – feedings by vein. They’ll start nasogastric drainage – suctioning bile from her stomach, through her nose.

She receives extra nutrition through an artificial umbilical line, blood products and medications through two intra venous lines. Before long, these veins will blow apart and they’ll go searching, again, for new sites. Before long, they’ll shave her scalp with a BIC to find new veins. They’ll present the brown fluff to me in a graduated 5 ml dosing cup, the kind you get with cough syrup. “It’s soft as down, it’s for her baby book, isn’t it cute?” someone says. After three more blood transfusions there are no more veins in her head. So they insert a plastic vein\textsuperscript{232} into her ankle. It worms its way through her body, feeds into to an artery near her heart. A 500 gram infant has only 40 mls of blood.\textsuperscript{233} New blood and antibiotics pump through her veins and plastic veins, from both the heart and the machine...\textsuperscript{234}

Jean Lantos captures the mise en scene of the NICU, poignantly in \textit{The Lazarus Case}:

The babies themselves did not seem quite real, or at least they did not seem central, except in a mechanical way, to whatever dramas were being enacted there. They are part of some vastly

\textsuperscript{231} Necrotizing Enterocoltis (NEC) is a common affliction associated with premature babies. It refers to the death of tissue in the gastrointestinal system.

\textsuperscript{232} Medical devices such as intra venous tubing, catheters, ventilation tubing and blood bags that are used in intensive care units for neonates are made of PVC vinyl, which contains a plasticizing chemical compound, or phthalate, called DEHP, or di(2-ethylhexyl)phthalate. DEHP is considered to be a reproductive toxicant associated with infertility, disrupted hormonal balance, testicular mutation, and atrophied testicles in males. Studies have determined that a safe daily level of DEHP is up to 30 micrograms per kilogram per day, for an adult. Blood sampling research has found that neonates in intensive care have as much as 200 times this level of DEHP in their bodies. Neonates can be exposed to toxic levels of DEHP for days, weeks, and even months. However, DEHP continues to be used to make medical devices that are used to treat vulnerable neonates and other patient populations. Related, Health Canada has recently banned the sale of container products, specifically baby bottles, containing the phthalate bisphenol A, a chemical compound that has also been proven to be notoriously toxic. See D. Helton in Marc de Guerre (Prod.) “The Disappearing Male” (2008).


\textsuperscript{234} Adapted from personal account. For further discussion of neonatology in the context of cyborg theory, see J. Smith-Windson “The Cyborg Mother: A Breached Boundary” in A. Kroker and M. Kroker (Eds.) (2004) pp.184-191
complex loop, feeding back upon itself, the energy source to which all is connected, and from which all disseminates. Part of a greater nervous system, or interface, perhaps? They were clearly the place where the tubes and wires and catheters came together. But they were clearly not the place where the eyes of the professionals focused. Instead, the professionals focused on the machines and the monitors, listening to the rhythm of the beeps, etching the flickering digits on the ventilators and the infusion pumps and the mysterious tracings across the amber oscilloscope screens representing the electrical activity of the babies’ hearts. Some of the tracings were reassuringly repetitive. Others were anxiously erratic. These patterns and numbers were, in a way, both a representation and a reification of the babies. The numbers and the patterns became the essence of some entity that might be called the “health” or “sickness” of the babies.  

The numbers are numbing. The staccato of acronyms are chillingly impersonal.  

This 26 weeker has RDS and a PDA; he’s on a rate of 30. PEEP of 5.35% O2. Neuro: an ultrasound yesterday showed a Grade II. Nutrition, he’s down 300 grams since birth, we’re starting TPN today. Heme, he’s had 3cc’s out and we’re replacing it. Social, parents haven’t been in.

The professional caregivers and parents learn and speak and understand this staccato language of bodies being transposed into pixilated codes and sterile acronyms. These codes are part of becoming wired into the nervous system of the NICU. And, as such, it is part of the process of becoming cyborg.

It is about “the simultaneous externalization of the nervous system and the internalization of the machine,” the symbiosis of human and machine that ultimately shapes cyborg consciousness. These codes are, simply, cyborg-speak.

February 26, 2003 - ...I look to the machines and they tell me how my daughter is doing today. How easy it is to look at the monitor that tells me, “she has the hiccups, she’s sleeping, she’s not breathing – not yet”...

235 Old technology. See J. Lantos (2001) p. 26n  
236 Lantos, J. (2001) p. 26  
In the NICU, pixilated hiccups dance, erratically on the screen one minute. The next monitor displays the pixilated code of breathing, pulse, temperature, oxygen saturation. I watch for the erratic patterns on the screen that read: apnea\textsuperscript{240}, or bradycardia\textsuperscript{241}. Breathing, not breathing.

The gazes of carers shift from the babies to the codes and back again. In their transparent incubators, the babies are fully lit up under halogen examination lamps, fully exposed in their radiant warmers. The babies become almost peripheral to the codes which denote their vitals, health, and neuro-normalcy. Babies’ splayed limbs glow under phototherapy lights, yet the gazes still shift away from their fully exposed bodies in their Plexiglas chambers, towards the machinic traces of vital signs flashing across monitors and screens and visual displays. Perhaps, “the human eye is not meant to see a fetus.”\textsuperscript{242} Perhaps the gaze rests, more comfortably, on the ambivalent virtualization of trauma-codes. Pixels are less complicated than the pure event of trauma.

*The ultrasound transmitter is the ambivalent interlocutor between the machine and my baby. The interlocutor, pressed against her fontanelle, transmits pixilated sonar shadows onto the sonographer’s screen in real-time. One grey shadow, in particular, caught everyone’s attention as we watched on. Those grey pixels, seeping across the screen, indicated that my baby’s brain was hemorrhaging, in real time.*

The ambivalent virtualization (=pixels) of trauma is far easier to look upon than the pure event of trauma itself (=blood). Pixels are more sanitary than bodies’ actual fluids. The codes are easier to engage with, “codes lack the seriousness of real life because they provide only the simulacrum of [pain, suffering, trauma, and] death”\textsuperscript{243}.

\textsuperscript{240} The suspension of breath.
\textsuperscript{241} A significant drop in heart rate, similar to a heart attack that is often accompanied by the suspension of breath.
\textsuperscript{242} Conn, N, “Little Man” (2006)
\textsuperscript{243} Hayles, K. in A. Kroker and M. Kroker (Eds.) (2008) p. 30
Flickering across the screen, the premature baby is composed of a series of special effects that are seemingly dreamed up by technology on the frontiers of medical progress. Codes, metaphors, and Pavulon allow for the effortless redirection of the gaze from the neonate to the screens which splay its virtual vitals in the sterile language of ‘data’. Here, transposed into the language of informatics, transposed into data, the neonate is reconstructed, differently, apart from the real conditions of its direct experience. “Disassociated from language, trauma resists narrative. When traumatic events are brought into the linguistic realm, they are frequently divorced from appropriate affect.”

The neonate evokes discomfort at many levels: clinical, personal, political, ethical, biological. Yet, the blurred boundaries between technology and flesh, turns babies into tinker-toys. In a tinker-toy kind of way, the NICU is a technotopia, a technological conjuring trick. It is pure technoluxe. Observers say: “This place is like a magnet to me. I can’t pull myself away. Why? Because it is like going in the best magic room at a state fair with all the latest lights and equipment and magicians performing fantastic tricks with the highest-priced prizes at stake – health and life…” Entering the NICU, “[is] like entering the twilight zone.” It never feels, wholly ‘real’. Practitioners say, “It’s like being in Las Vegas. You have no concept of what ultimately, your reality is.” It is, in a Foucauldian sense, pure spectacle with consequences both intended and unintended.

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244 Conn, N. “Little Man” (2006)
245 A potent paralytic.
246 Hayles, K. in A. Kroker and M. Kroker (Eds.) (2008) p.28
247 Lantos, J. (2001) p.92
248 The term technoluxe aptly describes the transformation of health services into discretionary ‘boutique medicine’. It refers to the growing capacity of medical technologies, products and services to medically manufacture designer bodies. Arthur Frank suggests that “Technoluxe depends, first, on the increasing public and professional acceptance of the body as something to shape and life as a project of shaping. It depends equally on the idea that projects are realized through acts of consumption.” See. A. Frank in E. Parens (Ed.) “Emily’s Scars” in Surgically Shaping Children: Technology, Ethics, And the Pursuit of Normality” (2006) p. 74
Some bodies fuse perfectly to the inexhaustible mimicry of the machine. But not all bodies ‘gel’ well with its gadgets, nodes and codes. Some babies are code-breakers. Sometimes, the babies break. Some babies loose the fatal end-game of pharmaceutical roulette. Some babies bleed, extubate, overdose, enter comatose. Some bodies become so septic, there feces have to be excreted from the stomach with a suctioning device. Some are so tiny, the nurses search, in vain, for veins, in the dark, holding flashlights against their near-translucent skin, looking for veins that haven’t been blown apart by needles or foreign fluids: blood, antibiotics, steroids, paralytics, barbiturates, total parenteral nutrition (TPN), anti-convulsants, and diuretics. Pain, the mute voice-over of this technological conjuring trick, is aesthetically pacified by pharmacologically-induced paralysis and sterile plastic breathing tubes which interrupt the audible articulation of pain. But beneath the composed veneer of paralyses, the baby must be writhing.

NICU babies make a claim about humanity by challenging the very limits of it. In this regard, the NICU is a world of exposed nerves. The irony is that humanity is largely unaware of the claim that is being made of it by the NICU. It operates mostly beyond the realm of human awareness. The NICU is part of what Katherine Hayles might call ‘technological non-conscious”. It is possible that they only come into focus in and through moments of rupture and breakdown and friction. Catastrophe. In other words, the seriousness of the claims that neonates make on humanity come into focus only after the baby breaks.

Just as the human eye makes sense of the neonate through its virtualizations, the human mind scrambles to make sense of the neonate. Pediatrician and bioethicist John Lantos writes:

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252 Intubation requires that the vocal chords are bypassed. The eerie effect of this is that babies cannot make sound, produce a cry, or any other audible noise.
253 Lantos, J. (2001) p.28
They look something like the strange Life Magazine pictures of babies inside the womb. The babies seem almost, but not quite, human, almost, but not quite, fetal. In their chimerical, half-human, half-machine state they seem not only helpless and pitiful but also exotic, threatening, futuristic, feral, untamed, barbarous. They evoke a strange mixture of sympathy and disgust. Their vulnerability calls out to us, and we want to help them, but there is also something repulsively buglike about them that makes us want to obliterate them. They shouldn’t be there, so vulnerable and so dependent on the machinery and technology of medicine.  

Metaphors play a powerful role in how the neonate is coded and conceptualized. Specific metaphors about NICU technologies and borderline babies convey, in an indirect way, how professionals, parents and observers feel about baby-rescue technologies and about preemies, generally. “Metaphors lead us to emphasize certain aspects of the relationship and minimize others.” For instance, the Nuer tribe of East Africa treats atypical neonates and prematurely born babies ashippopotamuses, mistakenly born to humans. After birth, “The ‘animals’ are put gently into a river, their ‘natural habitat’. The tribe asserts that Nuer infants are not killed (which is against the moral code of the tribe). In effect, they “do what is proper for young hippos.” The ready-made metaphor pre-determines the parameters of “human” and “non-human”, death and life, membership or non-membership. Metaphors are not benign; they naturalize our choices, desires and stigmas. In some cases, they allow us to pretend that an act is necessary when it is actually a matter of choice.

In contemporary NICUs, metaphors in neonatology over-emphasize the technicity of neonatal care while minimizing the conditions which the babies themselves live in: prolonged pain, sustained stress, and intense ethical vertigo. “Metaphors highlight some features and hide other features of their

255 Lantos, J. (2001) p.28
principal subject.”

Put differently, “Metaphors often highlight significant aspects of a relationship, providing us with concrete ways of thinking about the nature of the relationship.”

So what does it mean when the metaphors that swirl about the neonate in care are devoid of human characteristics? What does it mean when a neonate is shrouded in metaphors of war, high-technology, science-fiction, space exploration, extraterrestrialism, and ectogenesis? What does it mean that they are objectified as mundane items or transposed into animals or food through metaphor? Extremely premature babies are referred to in medical and bioethics literature, as lobsters, tinker-toys, peaches, voodoo dolls or Barbies. Neonates in intensice care are routinely metaphorically composed as nonhuman entities often even as forms of life others capture, dissect, or perhaps eat: “lobsters who have lingered too long in the pot”, “splayed and with knees bent like a frog”, “butterflies in a cage”, “like a bunch of grapes in the nurses hand”, “froglike: with wine translucent skin”, “plum dark and gelatinous”, a “nearly skinless purple organism.” They are situated on some new frontier, on the frontline, on a high-tech roller coaster, in triage, attended by practitioners in ‘fatigues’. They are alien, bug-like, machinic, cyborg or likened to grocery produce. They are rarely, simply, babies. Metaphors about the neonatal

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262 Lantos, J. (2001) p. 29
263 Lantos, J. (2001) p.91
265 Conn, N. “Little Man” (2006)
266 Lantos, J. (2001) p.29
268 Lantos, J. and W. Meadow (2006) p.10
270 Sprague, E. and N. Zimmerman (2008)
273 Lantos, J. (2001) p.28
body often emphasize the spectacle of baby-rescue technologies and the otherworldliness of bodies and NICU technologies. Only, “the issues here are not ‘mere’ metaphors and stories”.

Neonatal bioethics literature is adorned with metaphors, invoked to describe micropreemies, technology, the NICU, and limit/less medicine. One neonatologist says, “The baby’s little heart seemed to be quivering, churning, like an engine on a cold morning that coughs and sputters but won’t quite turn over.” Another says, “sometimes the babies just seem like a physiologic machines that we can keep going, like a motor that keeps turning over and finally catches.” Confidently, a neonatologist reassures the mother and father of a preemie, “the baby, like a half-cooked chicken, would in time “be done.” Other metaphors situate the neonatal body in “triage at the site of battle.” Parents of twins born at 25 weeks reflect, “From the moment of their birth, and still to this day, we feel like we are triaging everything and just hanging on.” Interns and residents in training refer to their profession as being “on the front lines” or “in the trenches.” A preemie parent explains, “The NICU was very much like a war zone, with the alarms, the noises, and death and sickness…You don’t know who’s going to die and who will go home healthy.” At one American hospital, “the staff jokes that it will soon report for work in scuba suits to treat 20-weekers swimming in a giant tank of amniotic fluid.” After repeated attempts to draw a baby’s blood, a pediatric nurse reacts to her patient’s racing heart rate and falling blood-oxygen level, saying “[t]his is like sky-diving to you.” One patriarch of modern neonatology in the West, Dr. William Silverman, observes how emerging practitioners in the field of

276 Harraway. D. “A Game of Cat’s Cradle” in A. Kroeker and M. Kroeker (Eds.) (20008) p. 53
278 Quoted in G. Whittier (1999) p.218
282 Silverman, W. p.85
283 Roscoe, K. in L. Tarkan ( 2009)
neonatology often use war metaphors to conceptualize the subspecialty of neonatology as a war-zone. “Young doctors who had endured the exhausting physical and emotional demands of complicated high-tech treatments, seemed to view the intensive care nursery as a war-zone – an arena where special forces and armaments were deployed against death and disability.”286 Bioethicist Jeffrey Baker explains how “the incubator story involved not a battle between two armies, but a series of forays led by their scouts into the unexplored territory represented by the newborn….it would be wrong to portray that territory as unoccupied.”287 Neonatologist William Silverman paints a similar scene:

The full social costs of this extremely expensive, aggressive, high-tech war on neonatal mortality have, for the most part, not been measured. The situation reminds me of the bitter lyrics of an old anti-war song,

“Once the rockets are up, who cares where they come down?”…

The myopic outlook of never-say-die neonatal warfare reminds me of the attitudes in the disastrous war in Vietnam. One of our officers justified the torching of all straw huts in a settlement with the explanation, ‘We had to destroy the village to save it.’288

Metaphors of war and imperialism, in particular allude to the implicit violence experienced by neonates, the presence of death, and the high-stakes nature of rescuing extremely premature babies. Commonly-used metaphors of war and colonialism clearly reveal that practitioners feel as though they are pitted against an ‘unnamed enemy’, presumably death, nature’s course, or even disability.

In so many ways, the micropreemie has become a disputed territory, an emblem of disputed borders living in “the shadow land between fetus and the viable newborn.”289. Concerning the role of the practitioner in decision-making, neonatologist Dr. William Silverman says, “the decisions of how far we can, or must, go in the deployment of high-powered medical weaponry – the line between ‘knowing’

and ‘doing’ in medicine – should not...be made by specialists. Medical warfare is not all that different from conventional war (‘the continuation of politics by other means’). It is much too important to be left to the experts.”

Within their incubators, the babies collect collateral damages, known in the medical world as adverse events, iatrogenesis, medical misadventure. Collateral damages mount: toxic pharmacological therapy, intraventricular hemorrhage, necrotizing intestines, retinopathy of prematurity, bronchopulmonary dysplasia. The lines between biochemical warfare and pharmacotherapy blur. The micropreemie’s system becomes a site of biochemical warfare, the isolette an Abu Ghraib where corporeal insurgencies are captured, and counter-terrorized.

Metaphors of war, destruction, space exploration, and colonial conquest swirl about the NICU.

“There is something dazzlingly and disturbingly ultramodern about the whole scene. It is as ambiguously beautiful as a space shuttle coasting gently to a landing on a five-mile-long runway, as a Stealth fighter jet swooping secretly through the sky ahead of its sound wave and without a radar image, as the Manhattan Project.”

News articles spectacularize micropreemies “The Size of a Coke Can!”

Mothers try to find language strong enough to capture the precarious essence of their tiny children: “he looked like a little bird!” Technology, too, becomes slightly more benign, when blunted by the language of metaphor. They have “blood pressure cuffs the size of bandaids, a heart the size of a cashew. And transfusions less than a teaspoon.” The NICU baby can be anything in metaphor-speak: angel, bird, an 1 lb. brick of butter. John Lantos writes, “Some were blindfolded, lying totally naked under banks of fluorescent lights like the tanning booth patrons at the health club.”

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291 Lantos, J. (2001) p. 29
295 Lantos, J. (2001) p. 25
Perhaps metaphors are part of the spectacle of neonatal intensive care. “The choice of words colors the case; no word is morally neutral. Each swirls the current…” Some metaphors shed light on the conditions of pain, suffering and trauma which underscores neonatal intensive care while other metaphors seem to conceal the preemies’ bodies suffering and trauma. For instance, by drawing on the familiar realm of Barbies, tanning booths, and Coke cans, trauma is naturalized, underacknowledged. Perhaps the imagination can’t effectively simulate the experience of a micropreemie. We resort to metaphor in order to avert the materiality of the preemie’s experience of pain and trauma. It is easier to make decisions about the fate of a peach, frog or a lobster than it is to make decisions about the life of a precarious newborn.

Some metaphors provide insight into how particular individuals regard an event or a scene. Sometimes those feelings can be detached, macabre or surreal, however. Consider some of the statements of practicing neonatologists and emerging practitioners in the field. “We can bring a peach back from the dead with the skills we’ve developed,” says one neonatologist. “I’ve made vegetables before,” says another. A NICU resident whispers, “What they do here is not medicine. It’s voodoo.” Still another says, “We go until the baby breaks.” When asked “Who gets saved?” an intern replies, “Almost anything. We’d resuscitate a Big Mac if we could.”

The NICU is a cybernetic scene, ripe with metaphors that evoke fantasies of high-tech ectogenesis:

In some ways, the NICU seems like a male fantasy of the womb as the sort of thing you’d build with Tinkertoys, little electric lights, and an erector set. Each baby is wired to and violated by a
tangle of tubes and catheters, probes and monitor leads. Digital readouts show, in flat screen, real time, the baby’s temperature, oxygen levels, breathing rate, heart rate, carbon-dioxide level, cardiac electrical activity... Often described as a high-tech rollercoaster, metaphors of high-tech, high-adrenaline science, serve as codes. “In a Tinkertoy way it’s really cool. Except that the babies should be baby dolls, Barbies who turn blue if they don’t get enough oxygen and wet their diapers when given the right amount of intravenous fluid. But they aren’t. They are real little people, and this spaceship, this high-tech roller coaster, this cyberwomb is their introduction to life on earth.” “One cannot possibly comprehend the keeping alive efforts of every single second of a preemies life. A tweak of this, the twisting of knobs, too much of this, not enough of that. Every system must be calibrated.” Every system is alarmed in anticipation of malfunction. Even the alarms have alarms in the event of system failure. The incessant bleeping of alarm signals in the NICU is perhaps the crescendo of the technological imperative.

**Neonatal Intensive Care and the ART of Breaching Bodies’ Borders**

Neonatology is part of a broader high-tech baby-making enterprise that is rewriting the rules of human reproduction. New technologies are becoming increasingly capable of altering human existence, and unleashing newfound powers of social control. By looking critically at neonatology, we can begin to understand the implications of emergent New Reproductive Technologies, Assisted Reproductive Technologies and Advanced Reproductive Technologies which are literally redefining birthing and bodies in accordance with the socio-political demand and desire for normativity, improvement, and/or enhancement. Neonatal intensive care and Assistive Reproductive Technologies raise similar specters,

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303 Lantos, J. (2001) p.29  
304 Sprague, E. and N. Zimmerman (2008)  
305 Lantos, J. (2001) p.29  
issues, and ambiguities, including, but not limited to: the surrender of human viability to more equivocal terms, the eugenic underpinnings of medical decision-making during the prenatal and the neonatal period, the influence of disability stigmatization in medical decision-making, and growing appetites for increasingly aggressive interventions in human reproduction. Niche-medicine such as neonatology is irrevocably, seductively, and rapidly paving the way for the alteration of human reproduction. It has never been more important to raise critical questions about the claims, assumptions and consequences of advances in clinical medicine.

The Nuffield Council on Bioethics acknowledges the effects of emerging technologies and medical interventions on human reproduction and the way we care for newborns, drawing attention to three concerns, in particular:

First, the astonishing speed of [technological] development; second, its inescapable effect not only on individuals, but also on their families and society generally; and, third, the fear it arouses that it may be interfering with the basis of life itself.  

With high-tech exuberance, neonatal intensive care is challenging the very boundaries of life and death. The limits of viability continue to be surpassed and blurred by burgeoning new technologies that aim to stave of neonatal death and ultimately ‘fix’ pregnancy. It is no longer possible to delineate a clear or apparent ‘threshold’ of viability. Instead, there is a dubious ‘gray zone’ of viability, where babies born between 20 and 26 weeks of completed gestation may or may not survive. The ‘gray zone’ is a recognized site of clinical and ethical confusion. Practitioners acknowledge that “we’re saving babies that we wouldn’t have dreamed of saving 10 or 15 years ago. We’re doing abortions right up until that point.” And sometimes, after. In countries with explicit policy, the upper limit for late term abortion is 24 weeks of gestation. ‘Therapeutic’ abortions are often permitted up to 25 weeks of

gestation. Yet babies born at the 24-25 week mark often respond to resuscitation and routinely survive. Prematurely born neonates as young as 21 weeks of gestation have been known to survive. The boundaries of life and death and the limits of viability have surrendered to immense uncertainty.

The routinization of high-tech births and pregnancies brings us closer to a future where human reproduction is an improved means of circumventing bodies’ errors. The neonate is born on the borderline between the proximate past of bodies with wombs and the imminent future of machined ectogenesis. Ectogenesis refers to “modern reproductive and visual technologies aimed at fulfilling the ancient fantasy of…conception and gestation apart from the maternal body.”

Scenes of ectogenesis are governed by intense machinic (machine + organic) ambiguity; the boundaries between technology and biology can no longer be distinguished. Symbolically, neonatology, along with other ARTs, excites the triumphalist fantasy of ectogenesis, manufacturing life outside of the womb. This all stems from the belief that we can mechanically ‘fix’ the imperfections of human reproduction in the same way that aggressive technologies in newborn care can effectively thwart the boundaries of life and death, and overcome bodies’ differences.

Efforts to improve upon pregnancies and human reproduction are widespread in contemporary medical practices. Highly aggressive, high-tech interventions are simply becoming part of the normalized experience of human reproduction, pregnancies and births. The hystericalization of birth defects, the pathological re-conceptualization of pregnancy and the implementation of rapidly advancing technologies of intervention raise the specter of eugenics in many burgeoning clinical practices. It may be that by normalizing the experience of high-tech interventions in human reproduction, we regularize medicine’s growing power to turn human reproduction into a social engineering project.

Prior to the 1960’s, the care of ill and premature babies was not very technologically sophisticated, expensive or particularly successful. One neonatologist says, “When I came into the field in the 1940’s the hospital environment for babies was simple – clean, warm. Nurses would feed the newborn babies. Those who were meant to survive did, and if they survived, they did well.”

Today, newborn care has become highly intervened, highly technical, expensive, and partially successful. Today, “the [neonatal] rescue movement is, like the eugenic programme, a myopic effort to improve on nature by increasing the ‘efficiency’ of human reproduction.” Indeed, neonatologists suggest that “if too many premature babies survive with neurologic deficits, the field would be judged a failure.” There is growing concern that aggressive interventions in human reproduction and newborn care and the accelerated implementation of new technologies will impact the experience of pregnancy and motherhood and social tolerances of disability. Neonatology’s powers of social control are growing.

Of particular concern is that the fate of ‘defective neonates’ is no longer biologically determined. Rather, outcomes are medically tailored to suit socially held beliefs about disability and impairment. The problem can be framed as follows:

Who is to make the decisions that would deprive a human, however defective, of a chance to live? What criteria in terms of medical, genetic, sociological and psychological knowledge shall we use? What safeguards would be required to protect us against a Hitlerian type of eugenics?  

What are the limits of caring, curing and culling? Ethicists, practitioners, parents, administrative authorities and guardians now have the power to make decisions about which babies are preserved, which can be ‘actively euthanized’, and which babies they ‘let die’. The stakes are highest for those babies that are held up to a yard stick of normativity and deemed ‘defective’. The controversial topic of

311 Lantos, J. and W. Meadow (2006) p.41
314 Lantos, J. and W. Meadow (2006) p.38
“killing” or “letting die” began asserting itself in the late 1960’s, when it became apparent that neonatal technologies were proving to be somewhat successful at rescuing borderline babies, many of whom survived with varying degrees of disabilities. Medical ethicist Joseph Fletcher addresses issues of killing or letting die. Faced with a ‘defective neonate’ Fletcher suggests that there are essentially four choices for practitioners; “One, to kill them; two, to starve them; three, just not help them; four, to treat and preserve them.”316 He goes on, “Are not the first three in that list actually gradations of the same thing? …The end sought is the same: the infant’s death.”317 The fundamental decision is purely a utilitarian choice, for Fletcher. According to Fletcher, practitioners must make one fundamental choice - whether an infant’s life is worth preserving. If not, then it is morally acceptable to kill, starve or neglect them.318 In more sanitary terms, Fletcher claims that it is equally acceptable to deliberately euthanize, withhold treatment, or forgo treatment for a ‘defective’ newborn. “Technology does not create a moral imperative for its own use…Technology does create a moral imperative to choose, to decide whether or how to use it. There is no longer an option not to choose.”319

Today, neonatologists and parents still grapple with the same available choices in a context of absolute ambiguity.320 Neonatologists report that family requests for the prolongation of life are coming with increasing frequency and that they are urged to “Do all you can”.321 At the same time, stigmas, fears and hysteria about disability shape decision-making in a profound way. Pediatrician, Edmund Hey, wrote that, “Parents often tell me…that they dread severe handicap in a young child more than death itself.”322 For many parents, death is the favored outcome to disability. For other parents, their

320 Lantos, J. and W. Meadow (2006) p.119
babies’ potential differences are embraced and valued, or irrelevant. In a context where the rules of life and death have been suspended, parents and practitioners are left to select, cull, nurture or preserve life. Decisions are often informed by conceptions of “the good life” and conceptions of “disability”, desires for normalcy and fears of disability.

The stakes are highest for these infants with so-called ‘defects’. This is evident in the NICU, and also in ARTs. In the context of the NICU, clinicians and parents must decide the fate of particular babies amidst clinical and prognostic uncertainty, where death is not inevitable. Technological advances have shifted the way we ask questions. It’s no longer relevant to ask, “Will this baby survive?” The relevant question seems to have shifted. “Will this baby have a severe disability?”

Eugenics stirs in the NICU. Also consider the extent to which prenatal testing for birth defects has become a naturalized, routinized part of pregnancies. “The introduction of prenatal tests has modified the expectations about childbirth and placed new social responsibilities on mothers and expectant parents to avoid the delivery of an impaired neonate.” Expectant mothers now routinely participate in routine screening for ‘birth defects’ and often choose to cull fetuses with identifiable ‘defects’. Obstetric interventions and Advanced Reproductive technologies have “changed a woman’s experience of pregnancy and initiated social and cultural changes about the meaning of motherhood and the acceptability of impaired children and adults. What the implication of these changes in the long run may be has yet to be established; not all may be benign…”

Nature hasn’t yet, in 160 000 years, perfected human reproduction. Yet the seductive notion of improving on procreation and bodies’ errors continues to fuel the acceleration of high-tech inventions.

323 Lantos, J. and W. Meadow (2006) p.96
324 Lantos, J. and W. Meadow (2006) p.97
into pregnancies and births. “There is a disturbing similarity between the eugenics movement…and the modern never-say-die undertaking in antenatal/ neonatal medicine.”327 Niche medicines such as neonatal intensive care and ART have become gatekeepers of quality control in a prevailing paradigm of perfection.328 Gene selection happens. Genetic engineering happens. Therapeutic abortions329 are performed in the interests of social hygiene. ‘Termination’ has become the dominant and accepted ‘standard of care’ for treating certain anomalous zygotes, fetuses and imperiled newborns.330 Non-voluntary euthanasia and selective non-treatment for disabled, premature, and ill newborns is widely justified by practitioners, policy makers, law makers, bioethicists and parents.331 Neonaticide happens.

Since the early 19th Century, the myth of progress and perfectionism has prevailed in medicine.332 The tension between perfection and imperfection is played out in terms of eugenics; eugenics being the ultimate phantasy of perfection. Modern medicine simply presumes that ARTs and neonatal interventions can and should perfect the pattern of reproduction. However, if neonatology is any indication, we may already be living in the aftermath of the failure of new technologies to perfect pregnancies and births. On the one hand, ARTs and neonatology may be caught up in the rebirth of eugenics. The irony is that new technologies may also reveal the immanent failure of eugenics our high-tech attempts to ‘fix’ pregnancies and births.

329 I am commenting here, specifically, on the use of therapeutic abortion justified by the prenatal diagnosis of a fetus with a genetic or physical anomaly of an unknowable degree. Here, the lines between medicine and eugenics blur. This issue becomes increasingly vivid in instances of late term abortions, where the termination may occur past the upper limit of viability that has been established in neonatology. Amniocentesis, for example, is a prenatal screen performed in the second trimester of pregnancy. Wait times for test results often mean that the pregnancy has entered the “gray zone” where, with clinical intervention, the baby may be viable. Many of the ultrasound tests available through routinized pregnancy monitoring programs can not accurately predict physical manifestations of conditions (dwarfism, Down’s syndrome), earlier than the third trimester.
331 See Miller, G. (2007) p. 82-83
332 Lantos, J. (2001) p. 149
The Seduction of Normalcy and the Desire to Fix

If technologies of baby-rescue are only partially successful, what fuels their popularity amongst professionals, parents and the wider public? Arguably appetites are fuelled by rescue fantasies, the technological imperative, desires for normalcy and anxieties about disability and difference. French physiologist, Claude Bernard (1813-1878), maintained that “science teaches us to doubt and, in ignorance, to refrain”\textsuperscript{333} Yet somehow the mantra, “Do something, anything!”\textsuperscript{334} has become the universal cry/demand for health care services, resources and interventions, despite the fact that many subspecialties are now treading into uncharted and unproven territory. Parents of extremely premature babies echo this mantra:

When she was first born, I was already thinking that whatever it took to keep this child alive, if I had to go into debt and live in a shoebox, I would live in a shoe box to keep this girl with us for the rest of our lives…I would make sure this girl would be happy.\textsuperscript{335}

Parents’ elevated expectations and demands for medically manufactured miracles feed rescue fantasies of practitioners.

Neonatologist William Silverman wrote of his own freewheeling rescue phantasy in a retrospective article about the overtreatment of neonates\textsuperscript{336}. A baby-girl was born at 22 weeks gestation. She weighed one pound and five ounces; she was known as Baby F. Keeping her alive was ‘high-adventure’ for a virtuoso technician:

He pinned a how-to article that he found in the *American Journal of Diseases of Childhood* up next to the baby’s incubator and carefully followed the instructions. He bolstered the baby’s breathing with oxygen and monitored her temperature and eventually stabilized it. Twice daily he injected nutrients and fluids under her skin until she could be fed through a tube that was laced through her throat and into her stomach.

\textsuperscript{333} Bernard, C. quoted in W. Silverman (1998) p.2
Then he began to improvise, going beyond the cookbook instructions. Each day he gave the baby small transfusions of his own blood – something that would be illegal today – on the chance that adult blood might have salutary effects.\footnote{Levy Guyer, R. (2006) pp. 16-17}

Baby F would go on to hold the longevity record for more than fifteen years at the Babies Hospital. She died after three and a half months. Practitioners often feel an “unshakable obligation to prolong life.”\footnote{Silverman, W. in R. Levy Guyer (2006) p.17} While medicine is often systematic, careful and methodical, rescue-fantasies can be immensely dangerous, haphazard, and uncontrolled. When doctors go beyond cookbook instructions, cautious rules are sometimes abandoned and care can become reckless as innovators search for the next magic-bullet.\footnote{Levy Guyer, R. (2006) p.18} “Let’s try it and see” exuberance meets dazzling new technologies that make it seem as though anything is possible. Indeed, “a great deal of clinical innovation in the NICU today is happening outside of formal research protocols.”\footnote{Levy Guyer, R. (2006) p.107}

Sometimes, parent’s hold elevated expectations about the technologies of baby-rescue, expecting much more from interventions, technologies, and practitioners than they can ever be expected to deliver:

The setting is tense, sometimes rushed, and usually emotionally charged. Parents may be so desperate to try anything - the therapeutic imperative – and so anxious as their baby hovers between life and death, that they may not actually hear how risky, how uncertain, or even how experimental a drug or procedure or other intervention is.\footnote{Levy Guyer, R. (2006) p.106}

Or perhaps the public has been whitewashed by miracle rhetoric and so effectively seduced by the technological imperative that we believe that medical technologies can succeeded where nature has not. It’s hubris to believe that neonatology can one-up nature, often to the detriment of babies.\footnote{Levy Guyer, R. (2006) p. 148}

Sometimes, parent’s anxieties and fears are steamrolled by rescue fantasies:
A full-term baby “got into trouble” one night…The baby’s father was watching anxiously as the neonatologist worked on the baby, trying to resuscitate him. At one point the father said, “Doc, if he is going to be messed up, you can stop right now.” But the doctor didn’t stop trying to resuscitate the baby nor did he say anything to the father.343

What anxieties underscored the father’s words? Do most parents fear disability much more than death?344 “Was it appropriate for that neonatologist to completely blow the father off?”345 Was the father’s request at odds with the doctor’s values, legal duties, or ethical responsibilities according to the Hippocratic Oath?346 What rescue fantasies played out in that scene?

In a very short period of time, new technologies have been implemented in the NICU. These new technologies greet babies with a medical cornucopia of surgical fixes, aggressive interventions, surveillance techniques, new drug therapies and extraheroic measures that prolong, conjure, and improve the lives babies. Arguably, the paroxysm of technology and intervention at birth has transformed birthing rituals and shifted expectations of healthcare services and our expectations of practitioners who provide care. “Health care systems today are complex, technically proficient, competitive, and market-driven. One outcome of this environment is the recent phenomenon in the health care field of “consumerism.””347 If neonatology is any indication, we have reached the crux of technoluxe. Technoluxe is a useful description that refers to the increasing and shared acceptance among practitioners and the public that the body is something to shape and life is a project of shaping.348 Here we reach the disturbing question that technoluxe raises. Is there anything wrong with using medicine to produce designer babies? Is there anything wrong with our desires to normalize babies as part of birthing rituals?

348 Frank, A. in E. Parens (Ed.) (2006) p.74
In the NICU, elevated parental expectations, medical idealism, practitioner rescue fantasies and a general heroic ethos are reflected in the disquieting tendency for parents and practitioners to deny any limits. As appetites for high-tech interventions grow it’s apparent that we’ve become enslaved to the technological imperative and succumbed to heightened expectations of medicine and technology. At the same time that we’ve become wholly seduced by the imperative to ‘fix’ differences in babies, we have succumbed to “those marauding, seductive, and unattainable notions of normalcy.” One mother describes the frenzied first days after the birth of her daughter who was born with achondroplasia, a form of dwarfism.

As the frantic first days unfolded, it seemed that all we could focus on was how to repair the flaws, and we would listen to anyone from a faith healer to a surgeon if we thought there was a “fix” for her in it. I remember thinking we can put men in space, surely we can fix this.

Often times, parents have to reckon with their own desires for their children, in particular when their children are born into a highly-medicalized environment such as the NICU. The mother goes on to say,

The first order of business was to come to terms with a few central desires, not the least of which is that most troublesome one – the desire for normalcy.

Often, parents’ own desires exceed the capacity of medical technologies and interventions to deliver upon them, although that gap is narrowing. Faced with the possibility of high-tech surgical fixes and interventions, parents are left, “seesawing” between their desire to alleviate differences in their children, and the need to protect their children “from those marauding, seductive, and unattainable

notions of normalcy.\textsuperscript{353} Ultimately, normalcy is not merely descriptive, but prescriptive in the sense that our subjective understandings of normal bodies are predicated by the assumption that we should ‘do something, anything!’ about bodies that are not normal.

The desire for normalcy stems from a conception of disability that is informed by a medical model. The medical model of disability assumes two things. First, it assumes that non-standard bodies are deviant and need to be fixed. Second, it performs a homogenizing effect on a fundamentally heterogeneous group of people whose only real connection to one another is that they vary from the normative, dominant subject in some way. At the core of the medical model of disability is the assumption that the problem with some individuals has to do with their bodies’ function, autonomy and performance. The impetus to fix naturally occurring errors fuels the medical model of disability and vice versa. At the same time, anxieties and fears about disability fuel the medical model, and vice versa. Disabled bodies have become repositories of social anxiety\textsuperscript{354} toward ambiguity and uncertainty. Medicine reduces this ambiguity and uncertainty “by assigning the anomalous element to one absolute category or another”\textsuperscript{355}: normal or pathological, healthy or septic, normal or abnormal, intact or disabled. These binaries enable strategic categorization\textsuperscript{356} which fuels evidence-based ‘research’, policy development and medical practice. As such, the medical model of disability is not merely descriptive, but tremendously prescriptive.

Organizing babies according to their normalcy or ‘deficiency’ is prescriptive in the sense that there is an implied imperative ‘to fix’ bodies’ differences and ‘deficiencies’. The imperative to ‘fix’ or improve bodies is rooted in the very foundation of modern science, and medicine in particular. Francis

\textsuperscript{353}Hedley, L.A. in E. Parens (Ed.) (2006) p.44
\textsuperscript{354}Garland-Thomson, R (1997) p.6
\textsuperscript{355}Garland-Thomson, R. (1997) p.43
\textsuperscript{356}For a discussion of Mary Douglas’ ‘explanation of ‘assigning category’ see R. Garland-Thomson (1997) p.34
Bacon, one of the founders of modern science, proclaimed his ultimate desire “to stretch the deplorably narrow limits of man's dominion over the universe to their promised bounds.”\textsuperscript{357} He declared that science had the capacity to unite mankind “against the Nature of things, to storm and occupy her castles and strongholds.”\textsuperscript{358} The technological outpourings of reproductive, obstetric, perinatal and neonatal interventions are a testimony to modern medicine’s preoccupation with the improvement of reproduction and babies. This preoccupation and the medical model of disability are also evident in the fears and desires of expectant and new parents, especially among parents of highly medicalized babies. One parent says, “There are dangers, both social and emotional in being different and a certain amount of safety in being normal…I am vulnerable to the enticing possibilities of a surgical fix that might bring [my daughter] closer to that safety zone of normalcy.”\textsuperscript{359}

The scientific fix is the ultimate seduction. “The narrative of the Scientific Fix can exert so much power over [the] imagination that the danger of iatrogenic damage might seem negligible or remote.”\textsuperscript{360} There is certainly evidence of this in the NICU, in cases where exceedingly aggressive experiments unfold; but it is also evident in cases where babies are assigned DNR code because a ‘poor outcome’ is projected for their future. In both cases, decisions are made without due consideration about the unintended iatrogenic damages that may occur as a result of over treating or eliminating babies.

In the same way that disability is predominated by a medical model, so too has the way we perceive ‘health’ become highly medicalized. Medicine enforces the “politics of health”, a Foucauldian term that speaks to the rationalization of “hygiene…bent not on aid but on containment through “curing”, and disciplinary regimes that “systematically control the body” in order to maximize its

\textsuperscript{357} Lindemann, H. in E. Parens (Ed.) (2006) p.184
\textsuperscript{358} Lindemann, H. in E. Parens (Ed.) (2006) p. 184
\textsuperscript{359} Hedley, L.A. in E. Parens (Ed.) (2006) p.43
\textsuperscript{360} Lindemann, H. in E. Parens (Ed.) (2006) p. 186
efficient operation and its ultimate utility”. The medical model of disability fuels this politic at the same time as it fuels anxieties about disability. Michel Foucault has theoretically elucidated the mechanism by which marginalized people (i.e. disabled) are reckoned with. Technologies of normalization enliven “a power whose task it is to take charge of life’s need for continuous regulatory and corrective mechanisms…Such a power has to qualify, measure, appraise and hierarchize, rather than display itself in its murderous splendor.” As such, technologies are not merely banal resources for medical projects. They are ideologically inscribed. They mask the dominant interest in maintaining control in society.

The medical model perpetuates and reinforces the anxieties and stigmas surround disability. The medical model of disability treats disability as if disability were a corrupted text, a misspelled code, a spelling mistake, a typographical error that needs to be eliminated or repaired by genetic or medical editors. As such, social and medical agendas blur into one another. The specter of eugenics shimmers. Rituals of strategic elimination unfold. High-tech termination rituals evolve. Politically correct sanitization rituals are naturalized. Neonatology rests on the ontological assumptions wholly attributed to the medical model of disability – the incubator can be understood as the reinvention of Procrustus’s bed. Those that do not fit the ‘bed’ must be altered, cured, stretched, or cut to fit the model.

In the NICU, strategic avoidance of disability is the norm, masked in the careful rhetoric of quality of life considerations. Race, religious beliefs, maternal age, family structure, socio-economic considerations are all weighed when deciding whether to continue or discontinue life-saving treatment.

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362 Michel Foucault quoted by S. Tremain in L.H. Davis (Ed.) (2006) p. 186
365 For a discussion of Mary Douglas’ explanation of the cultural solution to anomaly as elimination, see R. Garland-Thomson (1997) p.34-35
for critically ill preterm babies. Treatment decisions are also precluded by the pre-emptive valuation of the infant according to the likely future prognosis of unknown degrees of disability. Practitioners treat first and then assess the health status of the infant for tell-tale signs of ‘poor outcomes’ - disability. This assessment is where practitioners ‘wait for the baby to declare themselves’ as either normal, or deficient. Babies who have deficiencies are often culled through non-treatment decisions based on the social valuation of the perceived disability. It is rarely called into question that these babies are often issued do-not-resuscitate orders, based on indecisive evidence of a future tainted with disability.

**Miracle Rhetoric: A Vital Illusion in Neonatology**

Over one hundred years ago, there was unbridled enthusiasm for medical miracles. In the late 1800’s, poet, physician and essayist, Oliver Wendell Holmes, wrote:

> There is nothing people will not do, there is nothing they have not done, to recover their health and save their lives. They have submitted to be half drowned in water, half cooked with gasses, to be buried up to their chins in the earth, to be seared with hot irons like slaves, to be crimped with knives, life codfish, to have needles thrust into their flesh, and bonfires kindled on their skin, to swallow all sorts of abominations, and to pay for all of this, as if to be singed and scalded were a costly privilege, as if blisters were a blessing and leeches were a luxury.\(^{366}\)

That was then, and this is now. Today, when faced with a baby born at the cusp of viability, the mantra, “Do something, anything!”\(^{367}\) has become the plea for aggressive interventions when parents are faced with a preterm birth. Events, often successful and often haphazard, unfold from there. The promise of miracles is ever so seductive at a time when critical inquiries need to occur. “Despite

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\(^{366}\) Holmes, O.W. quoted in W. Silverman (1998) p.69

heightened awareness of the need for organized skepticism about all claims made in clinical medicine, it would be foolish to ignore the yearning of all sufferers for magic and certainty.”

Telethons, Telemiracle, March of Dimes. These are the outcries for magic, certainty, and medical progress, which feed on and perpetuate both the successes and often unorthodox juggernaut of neonatal medicine. The media helps to sell uncritical faith in medicine and technology, by marketing miracles with unbridled and triumphal optimism. Miracle rhetoric coupled with uncritical faith creates the “opiate effect of success”.

Headlines feed rescue fantasies of neonatal intensive care, shrouding it in the delirium of success:

‘Miracle Baby’

‘Amelia, the tiny miracle baby, goes home’

‘Miracle Baby born months early survives against tremendous odds’

“Miracle Baby” Born in Britain

Alberta parents of ‘miracle baby’ return home

‘Miracle-rhetoric’ is rampant in the media. The media touts technological prowess citing single instances of a micropreemies born “the size of a coke can”, “as long as a ball-point-pen” or of a successful surgery performed on an “infant heart the size of a walnut”. The media pays very little attention to the experimental nature and iatrogenic outcomes associated with neonatal medicine. It’s not

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371 Times Online (February 20, 2007) ‘Amelia, the tiny miracle baby, goes home’ available at: http://www.timesonline.co.uk/tol/news/world/us_and_americas/article1411793.ece
374 CBC News online (February 03, 2008) available at: http://www.cbc.ca/canada/story/2008/02/03/miracle-baby.html
well-known that neonatal heart surgeries were performed without anesthetic up until the very recent past. Or that routine administration of steroids to ventilated babies is linked with a rash of cerebral palsy among preemie survivors. Rather, ‘miracle’ propaganda is everywhere, often perpetuating uncritical faith in technological “fixes” for broken pregnancies. Despite critiques of media misrepresentations\textsuperscript{376}, the fact is, neonatal medicine wouldn’t get very far if it were to widely acknowledge the ethical messiness of rescuing liminal babies. Neonatologist John Stahlman says, “We [neonatologists] have allowed the media to publish our successes widely and minimize our failures.”\textsuperscript{377} Despite deep criticisms from neonatologists and practitioners that families have misguided expectations of medical science, they are well served by misrepresentation. “Achievement of Preemies is Found to be Near Normal,” cites a New York Times Article. Or, the Washington Post: “In Canada, Preemies Seem to Catch Up Later in Life.”\textsuperscript{378} Neonatology’s mounting collateral damage is the industry’s own best kept secret. The victims of neonatal medicine’s high-tech, ‘friendly-fire’ rarely finds voice in the media’s massage. John Lantos suggests that there is a tendency to idealize neonatal medicine and outcomes in a way that bears little resemblance to reality.\textsuperscript{379} It is almost as if by broadly celebrating the successes of neonatology, and under-acknowledging its failures, we can somehow prod reality closer to its theoretical ideal.\textsuperscript{380}

The line between harming and curing is often deliriously blurred when we invite aggressive medical interventions into bodies and the bodies of our babies in pursuit of ‘life-at-all costs’. Aggressive medical interventions are so widely available they almost seem mandated or inevitable. There are parents who offer counter narratives to miracle-rhetoric by refusing technological

\textsuperscript{377} Stahlman, J. quoted in H. Harrison (1993) pp. 643-650
\textsuperscript{378} Levy Guyer, R. (2006) p. 53
\textsuperscript{379} Lantos, J. and W. Meadow (2006) p.22
\textsuperscript{380} Lantos, J. and W. Meadow (2006) p.22
interventions or particular therapies for their premature babies. Sometimes parents choose a path of nonintervention for their premature or critically ill baby. Somehow, acknowledging, or allowing an infant to die remains taboo in Western medicine. These events are rarely publicized.

Often times, heroic measures are simply unleashed and the parents aren’t offered a choice about whether or not to resuscitate their preterm baby. In other cases, parents direct orders are directly overidden by doctors or administrators who follow hospital policy on resuscitation. Many parents of premature and critically ill babies recall that they weren’t aware that they had a choice about whether or not their baby would receive aggressive interventions at birth.

There are some well-publicized cases where parents’ expressed choices to forego resuscitation at birth were over-ridden by doctors or hospital authorities. In Michigan, when Traci Messenger went into labor 25 weeks into her pregnancy, and gave birth to a baby boy, weighing 1 pound, 11 ounces, the Messengers informed their doctor, that “they did not want the baby resuscitated after birth or placed on intensive life support.” The doctor was unwilling to consent to the nonresucitation plan and the baby boy was placed on a ventilator. Later, the father unhooked the ventilator and was charged with manslaughter.

Sarah and Bob Thorson, from Minneapolis, have publicly expressed similar concerns about the lack of regard for parent involvement in decision-making at the premature birth of their triplets:

I was 21 weeks into a triplet pregnancy and in labor. My husband asked the perinatologist about our options. “You don’t have any options,” the doctor replied…The triplets were born several weeks later, extremely prematurely. Within hours of delivery, one of the babies was hemorrhaging severely into his lungs and brain…I gathered every ounce of courage I had to ask the question I thought any responsible, loving parent would ask. “At what point do we say enough is enough for this little boy?” The neonatologist answered, “You don’t make those

382 Lantos, J. and W. Meadow (2006) p.103
383 Lantos, J. and W. Meadow (2006) p.103
decisions. We do.  

A Canadian couple from Montreal has also publicly questioned their lack of involvement in the resuscitation of their daughter, Eve. “We asked that Eve not be resuscitated, but they resuscitated her, nonetheless.” So often, technology is unleashed and unquestioned. Other times, advance directives are outright ignored. When a Texas woman by the name of Karla Miller was going into premature labor at 22 or 23 weeks of gestation, the parents requested that no extra-heroic measures be taken at birth. But Hospital administration over-rode the Miller’s express refusal of intensive treatment at the birth or their daughter, stating that “if a baby was born weighting more than 500 grams (1 pound and 1.6 ounces), they would resuscitate it.” When Sidney was born, she was blue and limp; she weighed 1.56 ounces.

The Millers expected the delivery room staff to wipe the vernix – the “cheesy varnish” that covers fetuses – off the baby, diaper her, swaddle her in a blanket, and hand her to her parents. But instead, a young neonatologist who had been sent into the delivery room by the hospital’s administrator … immediately “bagged” and “intubated” the baby and connected her to a ventilator.

Sidney spent nearly eight months in specialized hospital care before being discharged home, where she continued to require round-the-clock care for several more months. By the time of her discharge, the Miller’s million dollar insurance policy had been drained, leaving no ‘insurance’ for the rest Sidney’s specialized care needs throughout childhood and life. “There’s a motive for a for-profit health care giant to choose and make decisions for aggressive treatments.” Exclusion from decision-making and lack of properly-informed parental consent remains one of the biggest concerns of parents who have experienced the NICU.

High-tech intervention has become the default course of action in pregnancies gone awry or ended too soon. Saying ‘no’ to miraculous medical interventions deemed ‘heroic’ is not an easy task. More often than not, intervention is simply a ‘given’. When faced with unknown outcomes, it has become the norm to pursue aggressive treatment, despite the fact that “science teaches us to doubt and, in ignorance, to refrain”\textsuperscript{389}. By virtue of being available, innovations are held in much higher regard than simply ‘caring’ for children or ‘refraining’ from using aggressive innovative technologies. “Parents who turn away from aggressive medical intervention for their infants are sometimes scorned in this age of high technology and incredible advances.” \textsuperscript{390} Medical pioneers and “innovative” doctors seem to have more value than those who are inclined to “refrain” from innovations that may be haphazard. Still, there are many parents who defy taboo by keeping medicine at arm’s reach from their high-risk child. Amy Kuebelbeck, mother to Gabriel, writes eloquently of her experience of infant death and comfort care in her book, \textit{Waiting with Gabriel} (2003):

Maybe protecting this child would not mean the usual tasks of getting vaccinations, putting safety plugs in electrical outlets and installing gates on stairways. Maybe protecting the baby would mean keeping medicine at bay.\textsuperscript{391}

For a baby born with half a heart\textsuperscript{392}, the reality is, that “no one can fashion a whole heart out of half of one.”\textsuperscript{393} Like other experimental treatments available, treatments for Hypoplastic Left Heart Syndrome are accompanied with hubris, unimaginable pain, and a lifetime of uncertainty which tethers babies to the medical system, indefinitely. Gabriel’s parents recall, “We felt we would be parenting him in another profound way: we would be protecting him from the medical onslaught…sparing him from

\begin{thebibliography}{9}
\bibitem{389} Bernard, C. in W. Silverman (1998) p.1
\bibitem{390} Deborah L. Davis, quoted in Kuebelbeck, A. (2003) p.26
\bibitem{392} This condition is known as HLHS; Hypoplastic Left Heart Syndrome
\bibitem{393} Kuebelbeck, A. (2003) p.36
\end{thebibliography}
being turned into a "science experiment." Kuebelbeck writes, “maybe we too needed to heed the ancient admonition still given to doctors today: Primum non nocere. First do no harm.” Indeed, it may require more courage to let go of a baby at birth than it is to hold on. Many of the aggressive interventions available to critically ill and premature babies today contest this admonition, leaving many parents of highly intervened and medicalized babies asking “when does caring become cruelty?” Who is to say where the line between maleficence and beneficence is? Perhaps it is not a line is at all anymore, but a ubiquitous, transgressed border.

What does this have to do with the media? Simply this, that there are multiple stories of neonatal medicine. Some affirm the miraculous stories found in the media. Others do not. The media encourages public acceptance of the “gifts” of medicalized technological ‘progress’ without criticism. Public accounts of contemporary incubator babies underscore medicine and medical practitioners with inherent and uncritical virtue, instilling unprecedented faith in unproven, experimental, and often reckless child-saving practices. NICU experiments often end much differently than the media divulges. Consider the use of neonatal imagery during The BC Children’s Miracle Network annual telethon fundraiser (2003):

_The preemie from Bed #6 flashes across the screen, body bedaubed, publicly displaying its wounds. The mother cradles the child’s head; the human touch provides stark contrast to the plastic walls of the incubator. The voice-over is selling the miracle of medical treatment by way of paid membership to the hospital foundation’s ‘Sunshine Club’. What the commercial doesn’t say is that Bed# 6 was issued a no-code, a do-not-resuscitate order. Not long after the cameras had captured their miraculous photo-op, the baby crashed for the last time. The staff refused the miracle of resuscitation. The resuscitation-bag lay limp, the nurses two thumbs twitched. They

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399 The International Guidelines for Neonatal Resuscitation outline the preferred method of chest compressions: two thumbs are all it takes to generate a palpable pulse. See S. Niermeyer (Ed.) (2000)
stood actively idle beside #6 while the baby crashed. There they stood, idling, until the mother could be summoned.\(^{400}\)

While practitioners stand actively idle by the bedsides of babies whose outcomes are overshadowed by an anticipated disability, the media captures and sells the magic and mystique of medical miracles. The media props up neonatal medicine by playing on rescue fantasies.

At odds with miracle-rhetoric is practitioner pessimism about the outcomes of disabled survivors of neonatal medicine. Qualitative research suggests that neonatologist’s perceptions of disability are often exceedingly negative. They are often overly pessimistic about disability and the impacts of disability on families. One neonatologist claims that “there are cases where survival may not be the best outcome.”\(^{401}\) Another says that, “sometimes a treatment will yield an infant so devastatingly disabled that death would have seemed preferable.”\(^{402}\) Another claims that “survival…is clearly not the only, or, arguably, the most important measure of outcome.”\(^{403}\) Yet another claims that “seeing the babies who come back with severe disability makes you realize that probably there is an outcome that is worse than death.”\(^{404}\) Normalcy has become the fetishized determinant of health in a health care culture that equates ‘health’ with normalcy. One neonatologist says that “forgoing treatment…would not be unjust discrimination when the infant’s handicap was so severe that there could not be a meaningful comparison with an otherwise normal child.”\(^{405}\) Is there such thing as ‘just’ discrimination? Negative valuations of disability influence decision-making at the bedside, raising questions about decision-making in the gray zone, where outcomes are not always clear or known.

\(^{400}\) Personal account, unpublished, 2003.
\(^{401}\) Lantos, J. (2001) p. 80
\(^{402}\) Rhoden, N. in J. Lantos (2006) p. 77
\(^{403}\) Quoted in Levy Guyer (2006) p. 29
\(^{404}\) Neonatologist quoted in R. Levy Guyer (2006) p. 28
Accounts of ‘miracle-babies’ preoccupy the media’s attention and satiate the public appetite for medical miracles, while stories of misadventures in neonatology are under-reported. The public has a much bigger appetite for a sanitized version of neonatology, it seems. However, when ‘defective’ neonates do make headlines, they appear in the media as “Million-Dollar Babies”\textsuperscript{406}, in stories that emphasize the abhorrent costs that babies with disabilities will pose to the taxpayer or the state. The citizenship status of premature babies for whom disability is anticipated, is underscored by the financial burden of high-tech, neonatal intensive care, the costs of their future care and disability-related expenses. On the contrary, ‘intact’ “miracle” neonates are rarely held accountable for their expensive medical rescue. Their medical billing information is rarely publicized. Their uncontested miraculousness is wholly justified because they are deemed ‘normal’ and will presumably become ‘productive’ members of society.

Consider the accompanying caption to a photograph of a premature baby in critical care, as depicted in a Pediatric News Journal:

\textbf{Life: At What Cost?} This premature infant has a better chance of surviving than it did 30 years ago, but is likely to grow up handicapped. More and smaller preemies are being saved each year, straining the resources for their future care.\textsuperscript{407}

While neonatal medicine is touted as “miraculous”, stories of survivors with disabilities are often accompanied with negative costing analysis, right-to-die advocacy and better-off-dead attitudes. The differentiation in story-telling betrays an inherent negative eugenics at play. ‘Intact’ survivors are somehow more entitled to expensive life-saving technologies than patients who survive and are disabled. Again, it is as if an unspoken caste system informs baby-rescue.

\textsuperscript{406} Harrison, H. (1996) pp. 299-302
Discomfort with disabled babies is evident in four distinct spaces that have been explored throughout this chapter: the NICU, in metaphors, in ART (generally), and in the media. The extent to which disability is met with hystericalization and constant (yet subtle) stigmatization in intensive care environments warrants further discussion. In particular, by swerving through the compounding complexities of neonatal medicine, it becomes apparent that the prevailing model of disability in modern medicine is limited in its capacity to explain the multiple and varied accounts of disability that are entwined with neonatal medicine. It might be productive to consider disability with greater complexity. By opening disability up to its own complexities, it may be possible to entertain a new model of disability that is quite apart from stigmatization, apart from the medical model. To what extent is disability part of a hauntology? What does disability reveal about the ironic reversal of the paradigm of perfection? What does technology reveal about disability? These questions, among others, will be further explored in the next chapter.
Disability and Neonatology:  

A Nexus, a Hauntology, an (Im)Perfect Crime

Neonates are haunted by medical overtreatment at the same time as they are haunted by strategic undertreatment and all that is implied by undertreating specific babies. In the NICU, decisions are shaped by a conception of human quality of life that is underscored by eugenic notions and the desirability of normalcy. This has been established in previous chapters. What remains is the possibility that disability may also haunt medicine in ways that are often left unconsidered. By exploring the nexus of disability and neonatology in and through various critical theories, a conception of disability emerges that is quite apart from the medical model. First, this chapter explores how the relationship between ‘disability’ and neonatology can be understood, in Derridean terms, as *spectral asymmetry*. It posits an alternative model of disability, a conception of disability as a *hauntology* of perfection and the medical model itself. Wendy Brown’s theoretical work on hauntologies is central to this consideration. It may be productive to acknowledge the spectral-like qualities of disability and work towards a conception of disability that is rhizome-like rather than ‘deficient’, unpredictable rather than fixable. In doing so, this brings us closer to acknowledging that uncertainty may preclude certainty as the governing principle of modern medical progress, now and in the future. It may also bring us closer to a conception of disability that is quite apart from the medical model. There is evidence that neonatal medicine produces more uncertainty than certainty. As such, this chapter draws on a number of Jean Baudrillard’s hypotheses, namely, the *uncertainty principle*, *ironic reversibility*, the *Perfect Crime* and the *impossibility* of the *Perfect Crime*. These four mutually possible hypotheses are not unlike or unrelated to Martin Heidegger’s philosophical engagement with the *essence of technology* and *questions concerning technology*. Commonalities between Jean Baudrillard’s hypotheses of the *Perfect Crime* and the *impossibility* of the *Perfect Crime* and Martin Heidegger’s *questions concerning technology* are drawn
together and build towards a full appreciation that technologies may represent both ‘a saving power’ and an imminent danger. This intense theoretical interplay contributes to the milieu of concerns that arise from neonatal medicine, not the least of which are concerns about disability.

**Disability and Neonatology: Hauntology at the Nexus**

*When we have arrived at the putative end of history, should it surprise us if history reappears in the form of a haunt?*

Or that the haunt takes the form of a liminal baby? The borderline neonate haunts: morals, ethics, histories, boundaries, scientific progress. It may prove fruitful to consider them as part of a hauntology; apart from history and the linear project of medical progress and the prevailing paradigm of perfection. Extremely premature babies, wildly unpredictable, haunt the seductive notion of a normal, orderly body.

A hauntology is composed of specters. So, let’s focus, for a while, on this notion of specters, and the figurative conceptualization of borderline neonates as specters. In general terms, others claim that specters emblematize “the unmasterable, uncategorizable, and irreducible character of the past’s bearing on the present” and arguably, on the present’s bearing on the future, or the future’s bearing on the present. Why specters? Because modern science and medicine appear to be haunted by potent forces that are felt, but not seen, categorized, but not necessarily categorizable, conjured, but not necessarily exorcised: disabilities, illnesses, mutations, insurgent cells and errant codes and genes, anomalies, virulent forces. In other words, medicine is haunted by the uncategorizable spirits with

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which we need to learn to live\textsuperscript{410}. We may also need to ponder the extent that we have relinquished control of the human destiny to “a science of imaginary fixes”?

Simply put, specters emblematize a way of living “that cannot be harnessed to projects of reason, development, progress, or structure.”\textsuperscript{411} By reckoning with specters, we come closer to knowing – that our relationship to medicine may be mostly parody and based on imaginary solutions that we need to question. And, lastly, because when we engage with specters, it may be possible to\textit{ learn to live, finally}\textsuperscript{412}. “Learning to live means living without systematizing, without conceits of coherence, without a consistent and complete picture and without a clear delineation between past and present.”\textsuperscript{413} The NICU is haunted by the specters of disability, the ‘partial-successes’ of an industry committed to improving and fixing nature’s errors and bodies deficiencies. The industry response to disability in the NICU is to strategically avoid or eliminate disability from the record of medical progress. The other option is that we can learn to live with the specters of neonatal medicine. Learning to live with disability, “demands a reckoning with the messiness of bodily variety”\textsuperscript{414}, as opposed to inventing strategies that will obliterate, banish, neutralize or euthanize the heterogeneous group of people that we call, ‘the disabled’. It means reckoning with the failure of the paradigm of perfection. Everywhere in the NICU, the delightfully ambiguous specters of disability hover. They haunt by eluding the strategies of detection and deletion, by endlessly reinventing counterstrategies.


\textsuperscript{412} Derrida, J. (1994) pp. xvii-xx

\textsuperscript{413} Brown, W. (2001) p.146

Many neonates ‘pass’ as normal in the NICU and do not grow into their ‘disability’ status until much later, when their viability can no longer be ‘disarticulated’, ‘deterred’, ‘interrupted’ or ‘diverted’. The failure of medical technology to pre-empt disability is disconcerting to normative medicine. The unseen presence of disability haunts neonatal medicine. The failure of technology, combined with its inexhaustible success, allowed my own daughter to ‘pass’ under the radar and live.

I am glad she ‘passed’ for ‘normal’ in the nursery. By the time her brain bleed was found, she was out of the gray zone. She was beautifully, indisputably ‘viable’. I’m glad the sonar shadows depicting a real-time brain bleed and later, scar tissue eluded the sonographer for as long as they did. Week after week, the sonographer’s wand was pressed against her fontanelle, scanning for signs of aberration. The shadows didn’t betray her. Pixels concealed her imperfection just long enough for her to ‘pass’. The surveillance technologies failed the ritual of detection. I’m glad her coming out party was delayed. I couldn’t bear the thought of her spending her last hours in an inauspicious plexi-glass chamber, like so many children before her, with her Auschwitz style-haircut, and the surgeon’s penmanship on her abdomen. Like so many children before her, she may have been categorized ‘defective’, euthanized or subject to a non-treatment regime of starvation. I still can’t bear the thought of knowing that the last words she might have heard was the sterile staccato of alarms and the R.T. shouting “DNR!” across the nursery. I am glad the technology failed her. It is only through this critical failure that technology was also able to save her.

Disability is often felt, but unseen in the NICU. It is an unseen presence that is not always detected. In this way, it upsets the orderliness of neonatal medicine. In her book, Politics out of History, Wendy Brown characterizes specters in a way that may prove helpful, here. First, she nods to Derrida’s notion of “spectral asymmetry”. Spectral asymmetry is simply this: the moment when an unseen presence is met by an incapacity ‘to see’ it. The specter’s felt but unseen presence, twinned with our incapacity to see what looks at us - this disrupts conventional systems of knowledge and power. Arguably, disability, like a specter, hovers in the NICU. It is a felt, but unseen presence, beheld by those who are incapable of fully apprehending it. What a tremendous power it holds over those who cannot fully diagnose or predict it. As such, disability is the central hauntology of the NICU, against

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415 Personal reflection (2009)
which technology and all of her measures are unleashed. Disability, then, “wreaks havoc with the epistemology of empiricisms, [and] particularly with empirical accounts of power,”416 In its impossibly small way, the neonate haunts the dominant episteme, paradigm, and empiricism with their indeterminate capacity to shift-shape or morph into ‘otherness’ – in other words, to become extraordinary or disabled. In this way, disability is, as a specter is – furtive, untimely, rhizoid, asymmetrical, unpredictable, contra.

In the neonate, we come close to fully apprehending the force of specters, their asymmetry, and their invisible, timeless power. This is because the neonate hovers on the borderline between the complete failure of modern science and its complete and justified success. In fact, the neonate may occupy both spaces, simultaneously, as a boundary-crosser. Through the neonate, we come close to finally understanding disability as a kind of boundryless identity, asserting itself into orderly systems with specter-like furtiveness. In the context of advanced reproductive medicine, generally, and neonatology, specifically, we can feel the often unseen, previable presence of disability, yet we are incapable of seeing what looks so plainly out from the perfectly transparent plexiglass incubator – that between genesis and disability, there is a relationship, a nexus, an assurance that that birthing and destiny are ambivalent to the orderliness imposed on technology and wombs.

The extremely premature baby, with its translucent skin, transparent walls, and digitized vitals splayed on screens, echoes something about transparency that we’ve been told before, something that we should know by now; “when there is overall transparence, when everything can be seen, nothing can be foreseen anymore.”417 The beautiful irony of the neonate’s complete transparency seems to offer an assurance that bodies will always be delightfully revenant, regardless of machines or flesh or medicine

or the gamut of imaginary solutions unleashed by contemporary medicine. In a tragic way, the cybernetic face of medical progress means that misadventure and iatrogenesis can no longer be foreseen. In a delightfully irreverent way, the origins of disability can no longer be foreseen, either. Ironies are never lost. Birthing in its most primal and transgressed rituals will always be guided by the invisible power of multiplicitous and inconstant specters. Their ‘status’ is not empirically observable, but no less tangible for being invisible and furtive. Despite the powerful seduction of the summons to normalcy and the full array of technology and pharmakons unleashed to exorcise specters/disabilities from human birthing and reproductive rituals, the specter/disability continues to haunt.

The rhizoid behavior of specters reveals something about disability, and vice versa. Consider Wendy Brown’s observation about specters:

The specter begins by coming back, by repeating himself, by recurring in the present. It is not traceable to an origin nor to a founding event, it does not have an objective or “comprehensive” history, yet it operates as a force...We cannot control the comings and goings of specters, because they are by nature “furtive and untimely”; they “upset time”, just as justice must entail an upsetting of the present, a referral of the present back toward our ancestors and forward toward the unborn.418

The recurrence of specters/disabilities says something about human history and, ultimately about human destiny. Perhaps history, and even destiny, is haunted (and undone) by specters such as these – specters that the dominant paradigm tries so fruitlessly to exorcise.419 Perhaps it is our unavoidable destiny to continue the reinvention of the human body in ways that are incomprehensible, “in a manner that does not add up to a comprehensive account”420 of our body’s relationship to the present paradigm, episteme, history, future. In this way, specters/disabilities have an unmistakable, but invisible power that can be gleaned in the way we relate to fetuses, the unborn, the extremely prematurely born. We

have more to learn by “being-with”\textsuperscript{421} specters than we do through their exorcism. We have more to learn by “being-with” bodies’ varied choreographies and extraordinariness, than we do through the disappearance of bodies with differences.

The second assertion that Wendy Brown makes about specters is that they exist within an intense, ironic tension. They are figures that are at once, both conjured and exorcised. Medicine, specifically reproductive and neonatal medicine, demonstrates the extent to which we seek out and exorcise undesirable traits from bodies and pregnancies. “Nothing demonstrates the new power over basic biological processes so convincingly as the modern control of human reproduction…We have to shake ourselves to realize that in an amazingly short time, the levers of power which control humankind’s game of reproductive roulette have passed from the goddess of chance into the hands of the medical profession – antenatal and neonatal doctors are fast becoming an effective corps of biological and social engineers.”\textsuperscript{422} Through medicine, in particular reproductive, antenatal and neonatal medicine, we aim to cure, fix, delete, rewrite, de/select or terminate particular disabilities and/or anomalies in order to mark medical progress towards complete mastery over human creation. The ultimate goal of mechanical ‘mastery over nature’ is “the eventual elimination of the ‘illnesses of the body as well of the mind.’”\textsuperscript{423}

What’s the prognosis of medical mastery over nature? If nuclear and protochemical technology is any indication, “the more powerful a technology is at expropriating and controlling the forces of nature, the greater the disruption of our society and the potential destruction of life as we know it.”\textsuperscript{424}

In neonatology, the same technologies that we have charged with improving, fixing, curing and deleting

\begin{footnotesize}
\begin{enumerate}
\item Derrida, J. in W. Brown (2001) p.150
\item Rene Descartes’ ‘mechanical philosophy’, quoted in W. Silverman (1998) p.44
\item Kimbrell, A. in W. Silverman (1998) p.47
\end{enumerate}
\end{footnotesize}
bodies are simply reinventing new ways of conjuring the irreverent and revenant specters of disability. Ironically, by making disability the subject of exorcism, reproductive and neonatal medicine has conjured new disabilities. The more sought-after normalcy becomes, the more elusive it proves. Put differently, if “we can “take our own evolution in hand”, it will slip from that hand by the very impulse it has received from it”. Jean Baudrillard might offer a similar observation, that both technical and human systems will ultimately be undone by their own systematicity and that the pursuit of perfection will result in the invention of counter-strategies and the evasion of perfection itself. “Fixing” bodies through reproductive and neonatal medicine is about the seductive notion of perfection which “is like a virus; it escapes by endlessly inventing counterstrategies”. Disability may be the ultimate counterstrategic invention.

It should be clearly stated that the term disability is not useful in demarcating a category of people. “Disability” as a categorical term cannot simply prescribe or will a heterogeneous group of individuals into a homogeneous group. The term, then, it is only a useful fiction about bodies’ multiplicity and enduring capacity to resurface, again and again; renewing, repeating, recurring in the present, reinventing for the future. Disability is not traceable to a singular origin nor to a founding event, it does not have an objective or comprehensive history, yet it operates as a force. An undeniable force. And that force prevails, haunts, and cuts across histories of places, spaces, and progress. Uncontainable, disability can be read as a spectral hauntology of modern medical progress, continually finding new forms, upsetting the pathological drive towards homogeneity and perfectibility.

427 Baudrillard, J. (2000) p.79
with insurgent forms of being human.

In an intriguing way, counter-narratives of ‘partial successes’ and ‘misadventures’ in medicine and neonatology are part of a prevailing hauntology that ghosts modern medical progress. By studying the spectral stories of medically manufactured disability, by writing from the nexus of neonatology and disability, it is possible to see, for an instant, what technology has always revealed, in its particular way of revealing and concealing things. In the midst of medical technoluxe, the story of technology is unfolding, and that story is underscored by a deep-rooted, rhizomic irony. It’s revealing more uncertainty than certainty. In the same way that preterm babies haunt the orderliness of human reproduction, borderline babies may be part of a greater parody that is haunting modern science and medical progress. Jean Baudrillard’s watchwords suggest that, “[o]ur situation is wholly a pataphysical one…that everything around us has passed beyond its own limits…and [ironically] at the same time that things have reached a state of paroxysm, they have also reached a state of parody.”

Neonatal medicine has certainly passed beyond its own limits (biological, technological). The paroxysm of neonatology is evident in the technological and therapeutic exuberance that drives the baby-rescue industry towards ever-more aggressive interventions and surveillance at birth. At the same time, the NICU is also a parodic tableaux of human existence, medical science, and progress. It’s a parody of life and of death and a parody of the seductive notion of normalcy. That neonatal medicine produces more certainty in the world or that we even have precise control over technologies of baby-rescue is also parody.

On one hand, medical technologies of baby-rescue and reproductive refinement are so incredibly advanced and highly successful. On the other hand, they may be merely appropriating the means to imperfectly reproduce human beings. Simply put, neonatology is on the verge of being very successful

431 Baudrillard, J. (2000) p. 52
and completely iatrogenic, simultaneously. Neonatal intensive care may be both the complete realization of Descartes’ ‘mechanical philosophy’. It may also reveal the ultimate failure, “to make ourselves masters and possessors…of nature”\textsuperscript{432}. Go one step further. Neonatology may be deemed a complete failure because it leaves a wake of medical mishaps, but it may also reveal something necessary, inherent, primal or rhizoid about the pattern (or interruption) of perfect reproduction. Perhaps at the same time that (ordinarily imperfect) human reproduction is being appropriated by medical and technological means, we’ve merely transformed the way that human extraordinariness is produced.

If our contemporary situation has, indeed, passed beyond the lawfulness of modern science and into a context of imaginary solutions\textsuperscript{433}, as Alfred Jarry claims, we may be sitting on the threshold of pataphysics, or already living in its wake. In order to entertain these assertions, we must divest the history of neonatology apart from a linear, progressive notion of medical progress and begin to understand it in and through the language of parody, irony, specters, and imagined solutions (i.e., in pataphysical terms). We must entertain the notion that borderline babies themselves are something burgeoning on spectral. As they cross and blur boundaries, the very terms of living and dying become wholly ambiguous. Indeed, they function as tiny, haunting pataphors that seem to reveal just how far we’ve come from our original context and how it is we’ve come to live in a world sustained by the promise of \textit{imaginary solutions}\textsuperscript{434}. In borderline babies, it’s evident that the border between scientific laws and imaginary solutions have blurred.

At the very least and most the NICU is a highly evocative theatre that animates important critical questions, including the question of technology itself. Bodies born at the technological edge force the

\textsuperscript{432} Rene Descartes in W. Silverman (1998) p.44  
\textsuperscript{433} Baudrillard, J. (2000) pp.92-93 and p.54n  
\textsuperscript{434} Jarry, A. in J. Baudrillard (2000) p.54
hand of acknowledgement – we are living in the present renegotiation of the question of technology. At the same time, we are living in the present renegotiation of the question of bodies amidst transgressed borders and boundaries. At the site of these increasingly blurred boundaries, we are not only witnessing new purposes and human uses for technology, but also the “technological repurposing of the very meaning of being human.”  

The unintended or unquestioned consequences of the frenzied repurposing of human evolution, bodies and destiny need to be explored to their fullest implication. Will technology and biotechnology will be successful in “redesigning the future of human evolution…literally rebuilding gene-by-gene the artificial successors to the human species”? Redesigning the body, repurposing the human destiny; the stakes have never been so high, yet under-acknowledged.

The cybernetic speed of technological change and implementation has outstripped the atrophied pace of ethics, particularly in the context of medicine. Why is it that we’ve invested ourselves with such uncritical faith in repurposing human beings, redesigning human bodies and expropriating human evolution, when there is so “very little evidence that our social and political ethics have kept pace”?

Why is it that “we live in a culture of futurist technology with often backwards-looking ethics, panicked by the speed and power of change”? Why is it that we are complacent during the alteration of the human species by technology? Is it because we’ve come to believe, so uncritically, that our biological bodies are wholly inadequate? Is it because we’ve become so seduced by the technological

439 The premise of Stelarc’s high-tech, human/digital interface projects is that the biological body is so inadequate that it has been rendered obsolete. This premise fuels his prolific art projects that aim to extend the human body. See http://v2.stelarc.org/index2.html.
imperative and the promise that manufactured bodies will somehow be better equipped for the biopolitical future? Is it because efficiency has replaced ethics as the ultimate measure of progress?

In a profound way, the borders between self and technology have become increasingly invisible amidst substantial change. To be sure, the very terms of living and dying have been usurped and rendered subordinate to the officious powers of new technology coupled with the force of socio-political will. At the same time, the inherent and ironic tendency of technology asserts itself. Perhaps our non-thinking about the present renegotiation of human bodies, boundaries, and destiny stems from our preference to think that new technologies somehow make our bodies exempt from mutations, twists, uncertainties, errors, and paradoxes. It is as though by willing technology that we can somehow bring about the theoretical ideal that there will one day be bodies absolved of error. But what if uncertainty is the new reality-principle? What if by seeking to normalize and improve on bodies, aberration becomes the new normal?

Technology and Bodies: Heidegger and Baudrillard at the Nexus

To open up this discussion further, it is helpful to consider at least three different (but not incompatible) theories of technology. The first is Heidegger’s *questioning concerning technology*. The second theory that will be considered is Baudrillard’s posited *ironic hypothesis*, which considers the ironic reversibility of all things. The third theory of technology, also posited by Baudrillard, is that

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440 This is also a Stelarcian concept – that the body needs to be improved upon, or extended, in order to be fit for the future. See [http://v2.stelarc.org/index2.html](http://v2.stelarc.org/index2.html)
441 Kroker, A. “When Data Slams into the Human Condition, the Result is Here, There and Everywhere” in Synthetic Times – Media Art China 2008 (June 09, 2008) pp.1-2 Available online at: [http://mediartchina.org/essays/Kroker.pdf](http://mediartchina.org/essays/Kroker.pdf)
442 Kroker, A. “When Data Slams into the Human Condition, the Result is Here, There and Everywhere” in Synthetic Times – Media Art China 2008 (June 09, 2008) p. 3. Available online at: [http://mediartchina.org/essays/Kroker.pdf](http://mediartchina.org/essays/Kroker.pdf)
443 Heidegger, M. (1977) p. 3
of the **Perfect Crime** and the *impossibility* of the **Perfect Crime** are both observable phenomena amidst technological paroxysm. Finally, these theories are enlivened by threads of thought borrowed from the field of critical disability theory and observations from the field of neonatology. But, for now, let us consider Heidegger’s theory of technology as it relates to neonatology.

The premise of Heidegger’s questioning is that the essence of technology is not simply technological, or even machinic. It is not a summation of measurable feats and expansionist capacity to ‘do more’, faster. Heidegger considers how reality itself is being repurposed, so rigorously ordered in the wake of modern technology that it seems to be composed of stock parts, or, *standing reserve*, or *Bestand*. He ponders to what extent man has become so rigorously ordered that s/he is simply a standing reserve, an accumulated supply of stock parts.⁴⁴⁴ Perhaps the body itself is becoming *Bestand*? Accordingly, Heidegger claims that the essence of technology lies in “the way in which the real reveals itself as standing-reserve.”⁴⁴⁵ This, according to Heidegger, represents the ‘supreme danger’ of the essence of technology – that by allowing ourselves to become ‘stock’ we deny ourselves *poiesis*, the saving power of destiny, itself.

In many regards, the extremely premature baby passes into *Bestand*, reduced to the *techne* of living, emblematizing the repurposing of bodies as ‘stock parts’ for technology as it conjures life out of bodies, as if it were a manufacturing process.

Technology and indeed, our relationship to technology, are certainly immanently dangerous. But, it may also be infinitely promising, according to Heidegger, who cites poet Friedrich Holderlin:

> *But where danger is, grows*
> *The saving power, also.* ⁴⁴⁶

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⁴⁴⁴ Heidegger, M. (1977) p.28
⁴⁴⁵ Heidegger, M. (1977) p. 23
Simply put, the essence of technology is intensely ironic, both dangerous and hopeful. Like neonatology, the essence of technology is a catch-22, both macabre and miraculous, both infinitely dangerous and infinitely promising, both domineering and emancipatory. On the one hand, technology seems to reveal the repurposing of human destiny as Bestand, so rigorously ordered and so calculable that bodies are barely differentiated from the data which swirls about them. Recall the aftermath of the NICU – categorically filed in a four-tiered metal file box?

physiotherapy
occupational therapy
speech and language pathology
orthopedic surgery
neurology
cardiology
neonatal follow-up
psychology
nutrition
ophthalmology & orthoptics
plastic surgery
oncology
developmental pediatrician
audiology
social work
orthotics
daily living supports assessment
assistive technology team
early childhood intervention team
Otolaryngology
Community Living
Pharmacy
Intensive Needs Pupil Support Services
Specialized seating
Respite Worker
Advocate
Home Care
Bloodwork
EEG
ECG
Hepatic Hemangioma
Repeat Ultrasound
X-rays
Botox?
Surgery

Consider how the disabled body has become subject to ordering, for instance. An endless fix-it project. “Everywhere, everything is ordered to stand by, to be immediately at hand, indeed to stand there just so that it may be on call for further ordering,”447 further fixing, improvement.

Infanticide and the strategic avoidance of disability through selective termination rituals in Advanced Reproductive Technology and neonatology speak to how uncritically the human destiny is being reshaped and repurposed by the body’s passage into Bestand and how we are enslaved by technology and deep-rooted desires for normalcy. We have come to rely on a number of high-tech interventions and medical surveillance technologies in order to naturalize normalcy. Indeed, the body has become so rigorously ordered by modern technology and the medical paradigm that the social tolerance for disorderly bodies is narrowing, quickly. We have become so efficiently seduced and enslaved by the technological imperative that measuring the feats of technology has supplanted critical questioning about the essence of technology. Relevant questions abound. Are we becoming stock parts? Wherein lay the saving power?

While technology is immanently dangerous, Heidegger suggests by questioning the essence of technology, we can come close to poiesis, ‘bringing-forth’, unconcealment. The saving power. “The closer we come to the danger, the more brightly do the ways into the saving power begin to shine and the more questioning we become. For questioning is the piety of thought,” says Heidegger. If it can be accepted as a given, that 1) everything has an essence and 2) that the essence of all things is concealed to human beings, then poiesis is essential to the essence of being human. It is blossom-like – a way of revealing the essence of things concealed. He suggests that the essence of modern technology lies

447 Heidegger, M. (1977) p. 17
within what it reveals about essence and what it brings-forth from concealment.

So, the essence of technology is very different than technology itself. Technology refers to what technology is: incubator, catheter, ventilator, pharmaceutical. “Technology is a means to an end… [And] technology is a human activity”\(^{448}\), claims Heidegger. It is a contrivance. But it is more than that, too. It is possible that the essence of technology extends further than its instrumentality. In essence, technology is more about revealing than it is about manufacturing.\(^{449}\) You see, technology, has a particular way of revealing things.\(^{450}\) It is more than just its measurable feats. This much, Heidegger has told us:

> Technology is therefore no mere means. Technology is a way of revealing. If we give heed to this, another whole realm for the essence of technology will open itself up to us. It is the realm of revealing, i.e., of truth.\(^{451}\)

The essence of technology is a way of disclosing and unconcealing, of letting something come into presence.\(^{452}\)

What does this have to do with babies born on the borderline? Philosophy can offer some salience to first order ethical dilemmas when health care practitioners, parents and ethicists are faced with hard decisions around surgically shaping or medically manufacturing children. “Are we (with the best intentions, of course) treating [the] child’s body (and life) as Bestand, as raw material to be shaped so as to fit our (and presumably her) sense of what is natural, normal and orderly?”\(^{453}\) Consider the neonate, plugged in, vitals splayed, fluids and temperature calibrated. With each tweak and calibration, her body is summoned into the orderly performance of living, and all of the normative assumptions that

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\(^{448}\) Heidegger, M. (1977) p.4  
\(^{450}\) Heidegger’s view presented by J. Edwards in E. Parens (Ed.) (2006) p.52. The original reference can be found in M. Heidegger (1977) p. 12  
\(^{452}\) Edwards, J. in E. Parens (Ed.) (2006) p.52  
accompany our perceived notion of that orderly performance. Technology reveals the body as a calculable, orderable system of information.\footnote{Heidegger, M. (1977) p. 23} It demands that bodies be disciplined\footnote{Disciplined, in the Foucauldian sense.}, part of a vastly growing and increasingly anonymous and interchangeable standing-reserve.

Call it the will to technology or the technological imperative – we are seduced and compelled towards the complete mastery of technology and not by the piety of questioning concerning the essence of technology, itself. The imperative to rescue smaller and gestationally younger babies almost always precedes and supersedes the ethical questions that should guide the technology. Ethics yields to efficiency. It is this frenzied, overbearing, and insistent will to master technology that causes the critical questioning about the essence of technology to elude us. “The will to mastery becomes all the more urgent the more technology threatens to slip from human control.”\footnote{Heidegger, M. (1977) p. 5} The same can be said of bodies. The will to normalize bodies becomes all the more urgent the more they threaten the strategies of social control that are evident within contemporary medical and health care systems. Indeed, Heidegger warns of the technological imperative. We need to ponder it and watch over it and pay heed to it.\footnote{Heidegger, M. (1977) p. 32} He offers watchwords, warning against the irresistibility and frenzied-ness of ordering, the feats and capabilities of technology and our (perhaps) over-zealous will to master it.\footnote{Heidegger, M. (1977) p.33} It may be that in trying to master technology, we are coming dangerously close to completely eluding the essence of technology itself, and therefore, the essence of being. Ironically, it may be that we are coming dangerously close to the forgetfulness of being when we stop questioning the contemporary tendency of human beings to allow things, even bodies, to completely disappear into our use for them.\footnote{Edwards, J.C. in E. Parens (Ed.) (2006) p. 54} “Our largely unexamined need to

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\item \footnote{Heidegger, M. (1977) p. 23}
\item \footnote{Disciplined, in the Foucauldian sense.}
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\item \footnote{Heidegger, M. (1977) p. 32}
\item \footnote{Heidegger, M. (1977) p.33}
\item \footnote{Edwards, J.C. in E. Parens (Ed.) (2006) p. 54}
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fix things and order for the sake of ordering fuels our tendency to treat whatever we can find and creates an overpowering impetus for us to fix things.\textsuperscript{460}

Consider disabled bodies, anomalous physiologies, mutant genes, etc. In consideration of all the technologies that aim to intervene, ‘fix’, correct and normalize different bodies, the social tolerance for diversity and heterogeneity amongst human bodies is becoming increasingly narrow. The fear of disorder shapes our response to situations of emotional and ethical turmoil.\textsuperscript{461} Ultimately, according to Heidegger, we “will seek to efface anything that impedes such ordering”.\textsuperscript{462} Anything that impedes orderly ordering, we delete. We are compelled to normalize our bodies and the bodies of our babies, to seek an undifferentiated, anonymous, almost interchangeable body. “Why does the possibility of a fix seem to make almost inevitable our need to avail ourselves of it?”\textsuperscript{463} It just may be that in treating our bodies as \textit{Bestand} and shrouding ourselves in complete anonymity and rendering ourselves interchangeable we are denying ourselves the essence of technology, the unconcealment of our essence, and the disclosure of being itself. It may be that we are becoming dangerously close to what Heidegger calls, the forgetfulness of being.

Neonates epitomize one of the most powerful impetuses of our epoch “the need for these things readily to “disappear” into our use of them.”\textsuperscript{464} Technology accomplishes this so effortlessly. Swaddled in an abundance of technology, the borderline baby is an impossibly small and vulnerable body who is, already, disappeared into its utmost utility: normal citizen, orderly data, neuronormal. As such, NICUs “make a compelling moral claim upon society. This claim insists that we not turn our back on these tiny, vulnerable babies….NICUs [are] the epitome of our humanity, the measure of our devotion, the

\textsuperscript{460} Edwards, J. in E. Parens (Ed.) (2006) p.61
\textsuperscript{461} Edwards, J. in E. Parens (Ed.) (2006) pp. 61-62
\textsuperscript{462} Edwards, J. in E. Parens (Ed.) (2006) p.57
\textsuperscript{464} Edwards, J. in E. Parens (Ed.) (2006) p. 56
test of our will and the capacity of technology to order and provide order." Yet that is not the whole story, either. For at the nexus of disability and neonatology, we come face to face with disorderly bodies and otherness.

Heidegger notes that technology will always “seek to produce things that efface their own conditions of production.” Neonates, for example, usually efface the conditions of their production, eluding both conventional birthing and technologically mediated production. But, not always. What is terrifying for Heidegger is “the idea that human beings should mold their world in accordance with their continuing discoveries of their own deepest desires, desires that may radically change as we continue to discover them.” Molding our world according to our scruples and desires is frightful and ugly degeneracy.

It is certainly not frightful, ugly or evidence of degeneracy that we have come to rescue babies born too soon. That is not the assertion here. But it may well be that it is evidence of frightful, ugly degeneracy that we have ceased to care, or question or think critically about the culture of extermination that is unleashed and abetted by highly medicalized and technologically intervened birthing rituals. We are currently living in an era hell-bent and driven to invent an artificial destiny where bodies are, better, faster, stronger, more intelligent and equipped and beautiful. It may be that we are fuelling a stratagem of exterminism. The stakes have never been higher for ‘others’ who aren’t necessarily ‘orderly’. Disabled babies have become an endangered species in the melee of advanced medical technology and new reproductive technologies. So little thought has been given to the prospect that the sentinels of otherness may one day soon be extinct. That is one possibility.
The seduction of order and ordering, and the impetus to shape the environment, bodies, everything in accordance with proper regularity, with patterns and practices willed and enframed by ‘normality’ can disclose something about the machineries of neonatology. Through the neonate, we see the body’s passing into Bestand, the inevitability of becoming “raw material for human ingenuity to use in its attempt finally to order the world for the sake of order”\(^{470}\). By making bodies anonymous and interchangeable, by washing them in the dangerously modernist antiseptic of ‘normal’, or ‘citizenship’, perhaps we are willing the erasure of that which makes bodies truly what they are – poiesis. By allowing the body to pass into the project of its virtualization as Bestand and by becoming its willful shapers, are we eluding, or forgetting Being itself? When the baby breaks, it defies the rite of passage into Bestand and ultimately upsets the stratagem of order that drives us to produce ever more productive, intelligent, perfect human beings. Here, at the disorderly nexus of disability and neonatology, we come face to face with the possibility that perfection will also eventually be effaced by the conditions of its production. In other words, technology will be undone by the strategic pursuit for order and normalcy. This is another possibility.

We have become increasingly able to willfully shape the body to the contours of our desires and scruples.\(^{471}\) “We are dealing with an attempt to construct an entirely positive world, a perfect world, expurgated of every illusion, of every sort of evil and negativity, exempt from death itself.”\(^{472}\) It has never been so effortless to completely succumb to a culture of extermination by failing to ask critical questions of technology. Indeed, we have been seduced by the idea of creating an artificial destiny for ourselves\(^{473}\) – so much so that extermination rituals are widely socially acceptable. A discussion of Jean

\(^{472}\) Baudrillard, J. (2000) p.67  
Baudrillard’s theory of technology in relation to exterminism follows.

In *The Vital Illusion*, Baudrillard posits two hypotheses. The first is that through technology unfolds the Perfect Crime. The Perfect Crime is synonymous with the eradication of destiny and the complete extermination of otherness, difference, creativity, *poiesis* (the saving power of destiny). The stakes have never been higher. It may be that Holderlin’s famous phrase must also be reversed: “the more the saving power grows, the greater the danger.”

To be void of destiny represents, in Heidegger’s terms, “danger in the highest sense.” Baudrillard’s second hypothesis is that technology unfolds by way of objective irony. Technology is subject to both ironic reversibility and the Perfect Crime. The two hypotheses are not mutually exclusive.

For Baudrillard, technology fuels the unrelenting pursuit and extermination of all forms of otherness, which is, according to Baudrillard, the equivalent of ethnic cleansing. The complete void of destiny and the disappearance of otherness is the greatest danger, what Baudrillard calls, The Perfect Crime. According to Baudrillard, we have gone “beyond alienation, into a state of radical deprivation of the Other, or indeed of any otherness, alterity or negativity.”

Go one step further. Perhaps we have gone beyond eugenics and entered into a new state of crypto-eugenics, a trend without a trace. *The Perfect Crime*.

For Baudrillard, we are living in the era of the extermination of the Other – an Other no longer contained in the traditional categories of race, gender, ethnicity, religion or disability. Consider the following passage:

*It is the equivalent of an ethnic cleansing which would not just affect particular populations but*

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475 Heidegger, M. (1977) p.28
unrelentingly pursue all forms of otherness.

The otherness of death – staved off by unrelenting medical intervention.
Of the face and the body – run to earth by plastic surgery.
Of the world – dispelled by Virtual Reality.
Of everyone – which will one day be abolished by the cloning of individual cells...
No more otherness; identity and difference...
The perfect crime.477

So the Perfect Crime is about staving off death and the extermination of otherness. So is neonatal medicine. We are becoming increasingly capable and able to willfully shape our babies according to the contours of our desires and scruples, and the seductive notion of normalcy. At the same time, this technological capacity is being met with sustained discomfort with disability and otherness. Social fears about disability incite evermore aggressive and high-tech mechanisms, interventions, and technologies that aim to control disability, stave off death, and shape the raw materials of bodies according to sanitized ideas of ‘the good life’, ‘good citizenship’, and normalcy. There is evidence of this in the NICU, which unfolds as one strange, eugenic spectacle. In the NICU, babies are nurtured or culled, assigned aggressive interventions or DNR478 codes, often according to the perceived prognosis of the baby - normal or ‘defective’. By rapidly implementing new medical technologies, we are coming close to the full realization of a politically correct extermination ritual. This, Jean Baudrillard would call the Perfect Crime – where the technological capacity to exterminate otherness meets the imperative to preserve normal babies and cull others. In this way, neonatology is a tableaux of the Perfect Crime. That is one possibility.

That technology is the Perfect Crime, needs no real accelerant. It is already unfolding at cybernetic speed. It is rarely mitigated. Yet, the closer we get to the complete realization of the Perfect

478 DNR code = do not resuscitate order
Crime, something else occurs. A resistance, of sorts. A disavowal of the idealized vision of the world that is perpetuated by science, and medicine.\textsuperscript{479} Commenting on the ethics of cloning and scientific and technological experimentation, Jean Baudrillard says, “we can count on a fierce resistance from the mortal creatures that we are, a resistance that springs out of the depths of the species, its vital exigency, its refusal of any final solution.”\textsuperscript{480} Neonatology does not offer any ‘final solution’ to imperfect human reproduction, or to the social taboo of disabled babies. If neonatology is any indication, we are already experiencing the refusal of any ‘final solution’ to errant pregnancies and bodies. In the NICU, babies are culled and babies are preserved. Some babies are ‘normal’, others are disabled and some babies survive extreme prematurity with medically manufactured disabilities. Like a good parody, neonatology reveals the failure of complete social hygiene, eugenics, and the Perfect Crime by revealing its own systematized failure to wholly, successfully manufacture babies outside of the womb.

So, in the partially-successful baby-rescue enterprise, both the possibility and the impossibility of the Perfect Crime can be observed. Where the Perfect Crime and the impossibility of the Perfect Crime are revealed, Baudrillard’s second hypothesis can be seen – that is the objective irony, or ironic reversibility of all things. Ironically, by inventing strategies to improve on pregnancy and wombs and babies that epitomize the future, neonatal technologies are leaving a wake of medically manufactured disabilities. By seeking to medically manufacture babies, we have also learned to medically manufacture disabilities. On the one hand, technology is capable of delivering increasingly perfect bodies and designer babies. On the other hand, the desires and scruples which define the current paradigm of perfection continue to be met with unintended consequences and iatrogenic outcomes. In medical terms, these imperfections are called: medically manufactured mishaps, iatrogenesis, adverse

\textsuperscript{479} Baudrillard, J. (2000) p.28  
\textsuperscript{480} Baudrillard, J. (2000) pp.29-30
events, and neonatology’s mounting collateral damage. If neonatology is any indication, the Perfect Crime is possible, impossible, and wholly ironic.

What this suggests, in theoretical terms, is that Being will never completely disappear into or succumb to *Bestand*, the utmost utility and function of bodies and human beings. Human beings will always find ways to efface and evade their systematic repurposing for the order of modernity, social hygiene, progress, whatever. What neonatology shows, in clinical medicine, is that Being itself is subject to objective irony. Technology reveals the ironic reversibility of Being. Baudrillard says, “There is a strong probability, verging on a certainty that systems will be undone by their own systematicity. This is not true only for technical structures but for human ones as well.”

That is to say, that the more we try to shape the world according to our scruples and desires, the more they will be eluded.

Central to the possibility, impossibility and ironic reversibility of the Perfect Crime, is otherness. Otherness is the flux of error at the core of destiny. It surfaces and resurfaces as a reaction-formation to order (for the sake of order). Otherness is a necessary promise, promising that order, perfection and truth will always succumb to error. This much, Nietzsche has told us. Error is necessary to being. And that, “The erroneousness of the world in which we think we live is the surest and firmest fact that we can get our eyes on.” It is not hopeless or pessimistic to suggest that being and error are intimately bound. *On the contrary*. Why not reconceptualize error apart from negative ontology?

Perhaps our challenge is not to eradicate the world of error, or to find a ‘final solution’, but to overcome the thought that error (otherness) needs to be eradicated or ‘solved’ in the first place. Perhaps, error precipitates more ideas than truth. As such, the pursuit of truth is far less fruitful than living with

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481 Baudrillard, Jean (2000) p.78
483 Nietzsche, F. (1989) p.45
the constant flux of error and otherness. What remains for us to reconcile in this era hell-bent on inciting technology towards the extermination of otherness and the constant narrowing of tolerance and human variety, is whether or not we can finally relent that inherent, extraordinary, often surprising and whimsical flaws are not part of a purely ‘negative ontology’ about the human destiny against which all of medicine, technology and progress is bent on ‘fixing’. Heidegger’s interpretation of technology and human destiny as a negative ontology\textsuperscript{484} may have been incorrect. Remember that “…where danger is, grows/ the saving power also”\textsuperscript{485}? What if the saving power is not related to the perfection of human bodies at all? What if the saving power of technology can only be realized through the failure of the era of extermination and the impossibility of the Perfect Crime/exterminism?

Otherness is the reaction formation and naturalization of orderliness of the era in biotechnology, medicine, politics, and social relations. Consider how most neonates enter into Bestand seamlessly, conforming and responding to the regular rhythms of the ventilators with predictability. They are coaxed into some semblance of ‘health’ and ‘living’ by artificial means (\textit{techne}); an intravenous diet of fluids, mechanized breathing, and a plethora of other biochemical, pharmaceutical and mechanical interventions. In many cases, babies survive with little or no indication that their birth went awry. But, sometimes, the babies break. Instead of becoming Bestand, they become Other, disabled (\textit{poiesis}). And by surviving the Perfect Crime, these Others/babies defy the era of extermination, an era that as stacked up every odd against the proliferation of otherness. When this type of unexpected disorder occurs, “here begins the great revenge of otherness, of all the forms, which, subtly or violently deprived of their singularity, henceforth pose as insoluble problem for the social order, and also for the political

\textsuperscript{484} Baudrillard, Jean (2000) p.82
\textsuperscript{485} Holderlin, F. quoted in M. Heidegger (1977) p.28
and biological orders.486 Neonatal intensive care is certainly not the only moment where the tensions between normalcies an otherness are played out. The NICU is certainly an observable and enigmatic scene where it is possible to observe how reproduction has been expropriated by the utilitarian reshaping of bodies as Bestand. It is also possible to observe how some bodies refuse the orderliness. The twin stories of technology as the saving power and imminent danger play out in the NICU, where scenes of a great tension between techne (ordering) and poiesis (breaking with order) play out in unexpected ways.

When the baby breaks, something about the essence of technology is revealed. In these moments, technology also reveals something about Being and destiny. The complete forgetfulness of being is denied. In the same way that Heidegger posits that total forgetfulness is not possible, nor is the complete perfection of the human body, nor is the Perfect Crime rendered possible. There will always be bodies that break from their orderliness and, in doing so, they leave rhizoid traces of otherness that will always contest the stratagem of orderliness and that dominates contemporary times. When the baby breaks, we are reminded that erroneousness, not normalcy, is the surest and firmest fact that we can lay our eyes on. Disability, beautiful and rhizoid will recur, in all of its splendid, painful, and horrific forms, defying social, political and biological order – despite, in spite, and sometimes because of technology itself. All this is part of the essence of technology. And the essence of technology glimmers with objective irony.

There is a definite affinity between Heidegger’s interpretation of technology and critical theorist Jean Baudrillard’s conception of The Perfect Crime. This connection has been established by Baudrillard, himself, in both The Vital Illusion487 and nuanced in The Perfect Crime488. Baudrillard posits the notion that technology is the exterminator of Being, of mystery, destiny. Similarly, Heidegger

muses that the essence of technology is a catch-22. For him, technology represents a saving power, at the same time that it cultivates the ultimate danger of human destiny – the forgetfulness of Being. Arguably, there is one noticeable difference. For Heidegger, technology is the absolute achievement of metaphysics. According to Baudrillard, however, we can reach the other side of metaphysics, through technology. Baudrillard says that it is possible to “break through the mirror of technology, contra Heidegger, for whom technology is still the absolute achievement of metaphysics.”

How is this relevant to the question of technology in neonatal intensive care? By advancing a hypothesis that is apart from the heroic ethos that incites contemporary medicine and the expropriation of human reproduction, we arrive closer to understanding the ironic reversal of technology to its fullest implication. Indeed, technology “is becoming the ironic instrument of a world that we only imagine is ours to transform and dominate.” That the humans can effectively transform human reproduction, infant development outside the womb and the domination of nature is an illusion. It may be that in the complete success and failure of neonatal technologies, that technology reveals this vital illusion. The more we enlist technology in order to improve upon the world, our destiny, and human reproduction, the more we will come face-to-face with the irony of it all. If neonatology is any indication, we are involved in a game “whose rules we just don’t know and perhaps will never know.”

Baudrillard’s second hypothesis is that the essence of technology is deeply ironic. Technology is more than merely the means of furthering the dominant narrative of the Scientific Fix and executing the Perfect Crime. At the same time that technology moves an exterminist agenda forward, it leaves, in its wake, traces and signs of otherness, counter-intuitive identities, ironies, anti-codes. A constellation of otherness. In the context of contemporary medicine, technology/the body counter reacts their own

489 Baudrillard, J. (2000) p.82
490 Baudrillard, J. (2000) p.54
perfectibility through narratives of iatrogenic disasters, medical misadventures, adverse reactions, toxic Pharmako-therapy, prolonged pain and suffering, and sometimes, of unabated human experimentation. Technology is perhaps, willed not by a summons to normalcy, but rather, by something more primal: the disclosure of abundant error in Being, in medicine, in human reproduction. Indeed, technology has a way of revealing this purely beautifully, ironic. It’s so ironic that it is almost parody. Technology, then, must be understood apart from the banality of hardware or machinery. Rather, it is a way “in which the world of human beings is constituted”, in an abundance of error and miracle. In the context of the NICU, when bodies break and new, medically manufactured errors appear in the form of disabled babies, we get closer to understanding that human destiny is a complex and irresolvable interplay between error and miracle.

The body cannot disappear into its utmost perfection and banal utility without leaving traces of extraordinariness, otherness, or difference. Nothing can disappear without a trace. The bodies procured from errors of biotechnology, (soon) bioengineering, and expansionist modern medicine remind us of this, despite the systematic disappearance of naturally occurring anomalies through birth defect surveillance, genetic engineering, and therapeutic surveillance programs. When the body breaks from normativity, otherness is disclosed and so is the impossibility of the Perfect Crime. The disabled, the medically damaged, and the bodies that break in the process of their normalization: they become a constellation of others whose stories cut across time, paradigms, codes and history, to reclaim some memory of Being itself, Being that is a state of abundant erroneousness and miraculousness, a dialectic dance of codes and anti-codes, catch-22s. There is hope and optimism in this statement, for it signals the failure and reversibility of the era of extermination the possibility of a ‘new normal’ that will reckon with bodies’ infinite choreographies. It signals the failure of the Perfect Crime. It’s then possible to

I am using this term as Baudrillard might use it, not as it is over-used in medical miracle rhetoric.
“imagine that technology, by way of an ironic reversibility, might be an immense detour...a massive “clinamen”, a hidden strategy moving behind all our techniques and practices, an absolutely unpredictable movement that would finally bring us to the other side of metaphysics.”

It forces the hand of power to reckon with otherness rather than to uphold a culture of exterminism that gets by on a heroic ethos.

For Baudrillard, everything is subject to ‘objective irony’. This has been explained in both theoretical terms and in the concrete context of neonatal critical care. The full implication of objective irony is that “there is a strong probability, verging on a certainty, that systems will be undone by their own systematocity.”

So then, there is a strong probability, verging on a certainty, that the NICU does not merely represent a hyper-hygienic site of Great Confinement, an exterminatorium, nor a site of medically managed culling (of proportions not unequal to The Perfect Crime). Nor is it purely a eugenic space. Rather, the NICU reveals something, by taking us to the extreme horizon of technology. We are part of a new game and there are other rules. “…even at a scientific level: the more the object is persecuted by experimental procedures, the more it invents strategies of counterfeit, evasion, disguise, disappearance….it escapes by endlessly inventing counterstrategies.”

It is, of course, tragic and heart-wrenching that the dangerous powers unleashed in the NICU will cause great harm to babies born into experimental medicine, at the edges of possibility. It is also evident that we come close to the completion of eugenics as extreme measures of social control converge with growing technological capacity in the NICU and elsewhere in medicine. It is, however, radiantly optimistic that neonatal technologies are not wholly successful at ‘culling’ babies from the

495 Baudrillard, J. (2000) p.82
course human destiny. It is tragically optimistic that technologies that would otherwise erase the aleatory aspects of human reproduction and evolution, will inevitably fail by their own impulsive systematicity. “Through the most subtle procedures we deploy to capture it, isn’t the scientific object itself playing with us, presenting itself as an object and mocking our objective pretension to analyze it?”

Perhaps it is like this – the more we accelerate towards The Perfect Crime (i.e. in the NICU), the more the body will reinvent strategies of evasion, counter-strategies (i.e. a new category disabled survivors). Concerning the complete extermination of otherness and the fine-tuning and tweaking involved in manufacturing babies in contemporary medicine: “It seems that something resists this irresistible trend, something irreducible.”

Disability is part of that ‘something’, that ‘resistance’, that ‘irreducibility’, that defiant assertion of erroneousness as part of human destiny. Undoubtedly, this will have huge implications for the biopolitics of the future.

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497 Baudrillard, J. (2000) p. 54
**Conclusion:**

There are multiple sites of inquiry that have been laid out in this thesis. There are many more complexities to explore. As such, this thesis should be read as a precursor to a larger research project and further complexity. This is the philosopher’s task: “to go to the limit of hypotheses and processes, even if they are catastrophic,”⁴⁹⁹ even if it makes the world more enigmatic and unintelligible.

The questions raised in these chapters lay the groundwork for further inquiry. There are other tensions, forays, practices, and “grey-zones” that are part of the postconventional matrix of neonatal intensive care and extremely premature baby rescue. There are pressing ethical questions about viability that have yet to be considered. The impacts of NICU economics needs to be exposed and explored to the fullest extent. Comparative research between countries needs to be considered, in particular, differential access and outcomes of neonatal intensive care in developing countries versus North America. The use of experimental, off-label and unlicensed pharmaceuticals in the treatment of extremely premature babies requires serious engagement in light of patient-safety literature and the establishment of best-practices that include informed-consent processes. An investigation of legal forays about extremely premature and critically ill babies raise key questions about the rights of preemies and in clinical care and medical research projects. The usefulness of ethics, ethics committees and bioethics requires careful consideration. Among other pressing considerations for the future of neonatology are parent advocacy concerns and the impact of family centered care models in the transformation of neonatal intensive care services. As such, better inclusion of parent voices, public concerns, and preemie survivor narratives in research models will better reflect the experience and impacts of preterm birth on families and communities. Are communities and families equipped to

support preemies who may survive with lifelong disabilities? In what ways can they be strengthened so that preemie-survivors thrive? In what ways do our systems need to acknowledge and respond the growing group of preemie survivors that have medically manufactured disabilities?

At the outset, this thesis provided an in-depth survey of available data, trends and histories of neonatology, with a particular focus on American and Canadian contexts. Specifically, the first chapter explored the curious and alarming trend of rising preterm birth rates in the United States and Canada. Possible causes of rising preterm birth rates are social, environmental and physiological. Advanced maternal age, the increasing use of Advanced Reproductive Technologies and rising incidence of multiple births are associated with premature labor and delivery. There also seems to be some evidence to suggest that preterm birth rates are highest among those who occupy the lowest rungs of the socio-economic ladder or have less access to prenatal health care services. Racialized groups such as African-American mothers, Inuit and Aboriginal mothers have significantly higher numbers of premature babies. Drug toxicity and toxicity from plasticizing phthalates are also suspect. Finally, there is some evidence to suggest that economic organization, administration and expansion of contemporary neonatal medicine may also be related to rising rates of preterm birth. Because premature birth often has lasting health consequences for survivors, it is becoming a growing public and private concern that more babies are being born at the borderline of technological and biological possibility than ever before.

Following that, I traced the often curious and sometimes alarming evolution of neonatology over the last 100 years, exploring the sojourn of neonatology with French midwifery, early-American side-show culture, and the eugenics movement. What began as a post-war repopulation strategy in France later detoured through early-American side-show culture which eventually transformed into contemporary neonatal intensive care. The theatrics of early-American incubator-baby side shows resemble contemporary NICUs in number of ways. Neonatologist William Silverman writes,
I find it hard to ignore the resemblance between the theatrics of the side-show exhibits and the dramatic actions in present-day neonatal intensive care units...In both, I find a disturbing detachment from reality...The feeble infant is plucked up and deposited in a theatre-like setting in which superb technical experts make all-out efforts to support life.\textsuperscript{500}

From there, contemporary, hospital-based neonatal medicine was born. I suggest that much of neonatology still takes place on the frontiers of medicine, in a culture of supply and demand, where cautious rules are often abandoned in favor of technological mystique and, sometimes because someone profits. Contrary to its dubious beginnings, contemporary neonatal medicine almost always takes place away from the public eye.

Neonatal medicine is highly experimental and continues, unchecked. I draw on examples of experimentation with oxygenation, steroids, anticonvulsant drugs, new pulmonary surfactants and analgesics in order to tell the story of iatrogenic outcomes in neonatology’s past, present and future. Neonatal pain and the consequences of neonatal pain experiences are grossly under acknowledged, even today. Many other experiments in neonatology are just beginning. Often, informed consent is a farce.\textsuperscript{501} Arguably, experimentation will define the future evolution of neonatal medicine, as it has in the past. Liquid ventilation and high-frequency ventilation are currently being experimented with.\textsuperscript{502} Gene-therapy, regenerative medicine and stem-cell therapies will enter the NICU in the near future. Favorable preclinical trials involving stem-cell/umbilical cord blood transfusions for children with cerebral palsy and brain injury resulting from neonatal trauma or prenatal complications will certainly invigorate investigation by neonatologists in the coming decades. The remarkable research of Dr. Joanne Kurtzberg of Duke University in the United States suggests that the regenerative capacity of umbilical cord blood transplantation/transfusions may help to correct damage in organs, including the lungs and

\textsuperscript{500} Silverman, W. (1998) p.15  
\textsuperscript{501} Anonymous neonatologist quoted in W. Silverman (1998) p.78  
\textsuperscript{502} Lantos, J. and W. Meadow (2006) p. 87
brain.\textsuperscript{503} The use of stem-cell therapies in regenerating lung tissues following aggressive ventilation and lung damage in premature infants is also showing promise.\textsuperscript{504} In some ways the evolution of neonatal medicine has paved the way for reckless experimentation, in other ways, the experiment is just beginning. Experimentation will bear both fruit and poison, in the future of neonatology, as it has in the past.

In the NICU, the Pharmakon makes and breaks the rules.

Pharmakon is a Greek word which could translate as either cure or poison. Perhaps \textit{both}. For Jacques Derrida, the Pharmakon is theoretical concept that denotes an ambiguous condition of therapeutically purgatory, between injury and cure, between cure and poison. In establishing the pharmakon as a “founding paradox” in Plato’s Pharmacy, Derrida says:

This \textit{pharmakon}, this "medicine," this philter, which acts as both remedy and poison, already introduces itself into the body of the discourse with all its ambivalence. This charm, this spellbinding virtue, this power of fascination, can be--alternatively or simultaneously--beneficent or maleficent.\textsuperscript{505}

It may be that the pharmakon is the ‘founding paradox’ of the contemporary NICU. Undecidedly, pharmacology cures. Alternately, or simultaneously, pharmacology wounds, breaks, and disables. The effects of TPN, oxygen, steroids and anti-convulsants are both noxious and salutary, innovative and iatrogenic. Certainly, the technological/biomedical imperative perplexes sense with its inexorable capacity for ambivalence. The neonate is born into these rules and is both made/broken by

\textsuperscript{504} van Haaften, T. and B. Thébaud (2006)
\textsuperscript{505} Derrida, J. (1981) p.70
Accordingly, the neonate is heir to the Pharmakon’s double-bind, both the curative and injurious capacities of new innovations.

By exploring the full consequences and unintended consequences of neonatology, neonatal medicine is opened up to its own complexity. Chapter two examines premature birth and the grisly scene of the NICU by engaging with multiple narratives. The voices of parents, neonatologists, bioethicists mingle, providing an account of neonatology that is varied and complex. By making use of personalized accounts of neonatal medicine a picture of the contemporary NICU emerges that is both horrific and enigmatic, gritty and spectacular. Of particular interest is how disability operates as a powerful force in the NICU. By engaging with some of the complex issues around decision-making in neonatal care, it becomes clear that neonatal medicine draws from a medical model of disability and the core assumption that bodies and functions of bodies should be normalized so that individuals can lead meaningful and productive lives. Although it has become the default model that underscores how society relates to individuals with disability, it is not the only available model. By engaging these complexities, tensions and varied accounts of neonatal medicine, it becomes clear that there are issues at stake which are quite beyond the limitations of a purely medical model or account of neonatology, and disability, in particular.

In the NICU, the prevalence of metaphor-speak provides some indication that society has come to value spectacle more than actual events, or ethics, for that matter. Neonates are often metaphorically composed as non-human. I explore the ways that neonates are often metaphorically arranged as: lobsters, hippos, birds, peaches, aliens. They are the size of a Coke can, a lb. of butter, a ballpoint pen. They are mechanized, like an engine on a cold day. Metaphorically, the NICU is a fretful scene: war-torn, the site of battle, a roller-coaster. It is both magical and detached from reality, like: a conjuring trick, a roller coaster, a night in Las Vegas. It’s science fiction and deep space. At times,

metaphors reveal the attitudes of doctors and parents towards neonates and at times they conceal the real events of pain, eugenics, and iatrogenesis.

From there, I move into an analysis of neonatal intensive care and Assistive Reproductive Technologies. The two closely related medical specialties raise similar specters, issues, and ambiguities, including, but not limited to: the eugenic underpinnings of medical decision-making during the prenatal and the neonatal period, the influence of disability stigmatization in medical decision-making, growing appetites for increasingly aggressive interventions in human reproduction and the surrender of human viability to more equivocal terms. These consequences of tinkering with human reproduction are being willed through new technologies in neonatology and assistive reproductive technologies, a trend that requires broad critical and ethical scrutiny. Of particular concern are neonatology’s growing powers of social control.

It is important to draw attention to the explicit eugenic bias against so-called, defective, abnormal, deformed, disabled, impaired, damaged, or malformed babies and fetuses. The ‘defective neonate’ and the unborn ‘defective fetus’ are counterparts in a high-stakes end-game. The stakes have never been higher. In order to improve on pregnancies, niche-medicines are commiserating with a newfound danger, coming dangerously close to the realization of eugenics. In neonatology, “the whole argument against providing treatment based on the possibility of disabilities among survivors incorporates an implicit bias against the disabled.” It is as if an unspoken caste system has evolved and reorganized the way we care for (or do not care for) babies and fetuses, particularly those that occupy the ‘gray zone’ of viability. It may be that new technologies bring us close to the realization of a eugenic phantasy. Or, perhaps eugenics has already been reborn and is thriving, reaching new heights of

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509 Lantos, J. (2001) p. 161
efficiency through ARTs and technologies of neonatology. Or, it may also be that neonatology’s iatrogenic past and present signals the immanent failure of the technological imperative to completely reshape bodies according to our desires for normalcy. How so?

By productively engaging with the nexus of disability and neonatology, medical technologies reveal something about disability at the same time that disability reveals something about technology. To expand on this possibility, Jean Baudrillard’s hypotheses of ironic reversibility and the uncertainty principle need careful consideration, as do Heidegger’s questions concerning technology. Of particular interest to a meditation on the nexus of disability and neonatology is the possibility that technology is at once, ‘a saving power’ and an imminent danger and also that technology has a way of revealing things. It reveals the uncertainty principle and the ironic reversibility of all things. It reveals the possibility of the Perfect Crime and the impossibility of the Perfect Crime. As the NICU shows, we are coming very close to the complete realization of eugenics, but also its failure. I consider the possibility that the more we are able to shape our world according to our scruples and desires, the more our scruples and strategies will elude us. Every system will be done by its systematicity. Every strategy has a counterstrategy.

Disability is about perfection and imperfection and the ironic relation between them. It may be that the more we strive towards perfection (in bodies, with technology and medicine, for instance) the more we will discover their radical imperfections. In this regard, the nexus of disability and neonatology enlivens Jean Baudrillard’s ironic hypothesis ironic reversibility. The NICU emblemizes human efforts to improve on human nature, but in the effort to do so, we may have discovered something else instead. Ironic reversibility leads us to the inevitable point that we may have to reckon with radical imperfection not by obliterating it, but by learning to live with it.

Technologies of baby-rescue are only partially-successful in the sense that they are very good at
staving off death, but only somewhat successful at restoring bodies to normalcy. But this is not because neonatal sciences and technologies are not advanced enough. On the contrary. If neonatal intensive care can act as a barometer of technological and medical progress, we are living in the excess of technologies unleashed to ‘save us’ from the notion that human beings are imperfect, or at least inadequate for the future. It may be that we have even altered our destiny in the process of seeking out ‘improvements’. Or, it may be that we are simply living the illusion that we can shape our destiny so that all aspects of human existence conform to our desires for the improvement the species and the human destiny.

I consider the possibility that the simultaneous rebirth of eugenics (the Perfect Crime, imminent danger) is coupled with the immanence of its own failure (the impossibility of the Perfect Crime, the saving power). This may be crucial. According to Katherine Hayles, the moment where a pattern breaks from its expected outcome is “crucial because it names the bifurcation point at which the interplay between pattern and randomness causes the system to evolve in a new direction.” It may be that there is something more crucial, perhaps even socially crucial, than the perfection of reproduction and the human body by advanced medical technologies. Perhaps the failure of bodies’ perfection will cause the system to evolve in a completely new way. We cannot avoid or overcome differences. We cannot cure, exorcise or unplug them. Rather, we must learn to live with differences and the beautiful multiplicity of truth, accident, and changeability. The growing number of individuals with medically manufactured disabilities may serve as sentinels of the simultaneous rebirth and failure of eugenics, and the surrender of certainties to uncertainties. Ironies are not lost. In seeking more certain outcomes, we are confronted with more uncertainties. By acknowledging this, we may be able to learn to live with

510 Echoing Jean Baudrillard (2000) p.79
differences, but more importantly, we may be able to learn to live authentically, and so live wisely.
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