Theorising Disability as Political Subjectivity: work by the UIC Disability Collective on political subjectivities

MICHELLE JARMAN, SHARON LAMP, DAVID MITCHELL, DENISE NEPVEUX, NEFERTITI NOWELL & SHARON SNYDER
PhD Program in Disability Studies & the Department of Disability and Human Development, University of Illinois at Chicago, 1640 W Roosevelt Road, Chicago, IL 60608, USA

ABSTRACT  Disability studies has shown how therapeutic professionals and people with disabilities occupy opposite sides of a deep cultural divide, one that artificially bisects normalcy from ‘abnormalcy’. The philosophy of political subjectivity provides an opportunity to analyse the fraught nexus that exists between institutions and those who navigate them as professionals and ‘clients’. Our essay seeks to theorise the subject positions that emerge as a result of this often volatile intersection by offering up four critical vignettes: (1) an analysis of the systems and networks that characterise disabled transport within the Chicago Transit Authority; (2) speech therapy training and clinical practices designed for those whose articulation is diagnosed as inferior; (3) an African American clinician’s analysis of disability taxonomies applied to minority wards of the state of Illinois; and (4) an analysis of scapegoating at the national level in a class-action law suit regarding the ‘missed’ diagnosis of disability prior to birth. These overlapping cross-disability accounts seek to enact boundary crossings as the foundation for a new Chicago Model of interdisciplinary disability studies. The essay concludes with a discussion of the need to broaden disability coalitions as the terrain of political struggle becomes increasingly diverse and complex.

Introduction: Philosophies of Political Subjectivity
Sharon L. Snyder & David T. Mitchell

This essay, with its overlapping first and third person accounts, is intended to enact

Corresponding author: David Mitchell.

ISSN 0968-7599 (print)/ISSN 1360-0508 (online)/02/050555-15
© 2002 Taylor & Francis Ltd
DOI: 10.1080/09687590220148522
the insights of collective scholarship. In particular, we seek to discern, and then find means for bridging divisions between disability activists, advocates and those trained in clinical sciences. ‘We’, the authors, are current participants in the PhD programme in Disability Studies at the University of Illinois at Chicago. During the spring of 2001 we undertook, as a collectivity, to conceptualise the ways that disability could constitute a post-modern political subjectivity.

With this goal in mind, we defined the scope of political subjectivity itself: theoretical work that seeks to apprehend the ways in which social institutions (families, schools, prisons, militaries, economies, professions, disciplines, languages, narratives and fields of knowledge) and those ‘subjects’ who enter into a relationship with them (willingly or not), produce each other as comprehensible. We anticipated that our findings, issuing from strong commitments to the growth of disability studies as praxis and as an academic field, would map the ways that institutions produce and reproduce disability as pathologised conditions and as populations in need of restrictive cultural oversight.

Our selected reading included landmarks in social theory and philosophy that analyse, from a scholarly vantage that neither identifies as disabled nor as disability studies, the interchange of bodies/minds as they intersect with oppressive social orders:

- Michel Foucault’s *Madness and Civilization* (1988) and *Discipline and Punish* (1995);
- Judith Butler’s *Gender Trouble* (1999) and *The Psychic Life of Power* (1997);
- Ernesto Laclau & Chantal Mouffe’s *Hegemony and Socialist Strategy* (1985);

We knew that such an undertaking would include:

- conceptualising the institutional and psychological dynamics of systems that manage disabled people;
- research into the ways in which many of us maneuver through such systems.

We furthermore did not want to apply disability studies at the cost of excluding clinical and therapeutic sciences, and instead sought out potential alliances between two unlikely groups: those who have been named as the recipient bodies of therapeutic interventions and those who have been trained to wield the authority of classificatory management and diagnostic schemes. As a result of this dual focus, we ended up in an analysis of the rhetoric, practices and taxonomies that have placed different members of our own collectivity across professional divides. We found that research protocols, measurement biases and policy mandates that view disability as a matter of ‘special needs’ inevitably collide with the efforts of disability studies to research how disability operates as identity, social perspective and human ‘knowledge’ base.

In taking up this effort, then, we sought to cross over some risky terrain: how might disability studies optimise the experiences of those who have also undergone a rigorous clinical and professional training? What could we glean from experiences where one moved from the position of the surveyed to that of the surveyor? What
new subjectivities emerge when one intersects disability studies with professions designed to ‘fix’ those who come within their purview? How are those trained in interventionist and adaptive sciences required to reproduce practices of norms and averages that disempower disabled people?

Finally, we endeavored to articulate what we refer to as a developing Chicago model of inter-disciplinary disability studies. [1] Professionals participating in the clinical sciences and politicised advocates/disabled people often find themselves situated on the opposite sides of a deep cultural divide: one that artificially bisects normalcy from ‘abnormalcy’ as if disability remains solely on the ‘recipient’ side of the social services and therapeutic equation. For instance, professional training protocols reward those who espouse disciplinary values and practices that often prove objectifying to people with disabilities.

Theories of political subjectivities provided us, then, with opportunities to investigate potential intersections between the individual diagnostic practices of psychology and the social arena of policy and economics. Disability studies research has effectively shown how psychology offers only limiting discussions of singular pathology (Shakespeare & Watson, 1997; Siebers, 2002). In contrast, policy studies and the social sciences tend toward an overview of oppressive social structures without reference to the psyches and bodies who populate and prove subject to them. The philosophy of political subjectivity provides an opportunity to analyse the fraught nexus that exists between the macro- and micro-levels of disability as a social construction. Largely drawing upon traditions developed in the wake of Freud, Marx, Nietzsche and later, Foucault, what we are calling ‘philosophies of political subjectivities’ theorise interactions between psyches and systems. This line of inquiry can yield a better understanding of the psychological coordinates of disabled people and disability professionals as they negotiate the ideological minefield of the interventionist disciplines.

Our analysis of political subjectivities also consisted of the reconstruction of a history of named biologies that have ordained and disqualified bodies for social privileges. For Foucault these bodies include those of ‘the mad’ and the medically ‘pathological’; in Butler’s case, bodies are gendered and sexualised as ‘deviant’; Laclau & Mouffe designate minority populations seeking to harness power against dominant totalitarian forces; and Zizek analyses the structures of fantasy that define and constitute the production of social scapegoats.

Following our discussions of the potential utility of these models for Disability Studies, each participant applied and presented some aspects of these analytical frameworks to questions pertinent to their own background and subject roles. These include:

(1) an analysis of the systems and networks that characterize disabled transport within the Chicago Transit Authority;
(2) speech therapy training and clinical practices designed for those whose articulation is diagnosed as inferior;
(3) an African American clinician’s analysis of disability taxonomies applied to minority wards of the state of Illinois;
an analysis of scapegoating in a class-action lawsuit in France regarding the ‘missed’ diagnosis of disability prior to birth. Each of these cultural sites, then, provided an opportunity for analysing the production of disability subject roles with respect to an array of official practices. They furthermore supplied us with locations for discussing processes of ‘subjection’ that characterise disciplines of knowledge and those who are trained within them.

**Channelling Deviance: Disability Transportation as Panoptic System**

*Sharon Lamp*

Foucault’s observations are often made from the remote location of an observer who examines behaviour and not experience; he is an expert by the surveillance he seeks to critique. In his essay ‘Panopticism’, Foucault accounts for the panoptic form of surveillance and discipline without exploring its effect from the recipient’s location—and what it means in everyday life. From a disability studies perspective, the lack of data on how the panoptic process of normalisation affects people labelled and socially constructed as ‘abnormal’ or non-disciplinable is notable. The purpose of this analysis is to examine how panopticism is applied to forms and spaces that cannot be coerced or molded to meet normative standards—namely, to people with disabilities.

Nineteenth-century architect Jeremy Bentham, coined the term ‘Panopticon’ when he designed prison architecture based on the principles that power should be visible, unverifiable and economically produced through the appearance of surveillance that, over time, will become an internalised and self-perpetuated state of mind. Bentham’s design allowed prison guards to see continuously inside each cell form the ‘panopticon’, which was the central observation tower, without the prisoner’s knowing when or by whom they were being observed: ‘A superb formula: power exercised continuously and for what turns out to be minimal costs’ (Gordon, 1980, p. 155).

Foucault writes, ‘one of the primary objects of discipline is to fix; it is an anti-nomadic technique’ (1995, p. 218). This generalised formula allows Foucault to follow the evolution of disciplinary systems from the fifteenth to the nineteenth century, by which time the category of ‘abnormals’, in what Foucault referred to as a ‘formula of exclusion’, had expanded to include ‘[p]oor vagabonds, criminals, and “deranged minds” [who] would take the part played by the [Fifteenth century] leper’ (1988, p. 7). He describes the panoptic approach to discipline that came out of the nineteenth century as an disciplinary mechanism that operates through general surveillance in the open spaces of society: ‘a functional mechanism that must improve the exercise of power by making it lighter, more rapid, more effective, a design of subtle coercion for a society to come’ (1995, p. 209).

Bentham described panopticism as—necessary modifications excepted—applicable ‘to all establishments whatsoever, in which, within a space not too large to be covered or commanded by buildings, a number of persons are meant to be kept under inspection’ (cited in Foucault, 1995, p. 40). Today we see panoptic practices being adapted and applied to various systems that are negotiated in
everyday life—education, taxation, police and security, medicine, etc. A good example can be found in twenty-first century American systems of public transportation, those that function to move masses of people efficiently. This form of social control is carried out through systems of classifying, organising and controlling the riding public. These systems resemble in microcosm the panoptic principle of visible, but unverifiable surveillance, as well as the themes of centralised, efficient observation through surveillance and coercion. By looking at the rapid rail method of transportation in the US city of Chicago, for example, the panoptic elements at play and the effect of the panoptic gaze emerge.

The panoptic gaze is pivotal in all phases and layers of the Chicago transit system. It is the imposition and the anticipation of the gaze through which coercion and control is ultimately achieved, and the movements of bodies are influenced and manipulated. General panoptic mechanisms can be found in the placement and use of transit observation booths, as well as visible, but functionally unverifiable, cameras located in subway stations and on train platforms. Almost all riders are aware of and become accustomed to the presence of communication-equipped transit personnel, both plain clothed (unverifiable) and uniformed (verifiable), but still often hidden among transit crowds. As Bentham predicted and Foucault diagnosed, the gaze has become omnipotent; a visible and unverifiable, but seldom considered, force in the transit experiences of ‘normal’ riders. However, for riders recognised as ‘abnormal’, the gaze initiates a barrage of separate and exclusionary treatment.

The authority of the panoptic gaze is evidenced the moment abnormal bodies enter the public domain of Chicago transit stations. Non-conforming bodies are identified, separated, coded as ‘1043s’, and expected to participate in an endless tirade of separate and additional interactions:

- from the ‘handicapped only’ turnstile (located closest to the stations’ observation booths);
- the status board that regularly reports outages of accessibility equipment;
- the separate path to the elevator;
- the special call buttons to request boarding access;
- preparation of separate paperwork;
- the reporting of ‘1043s’ to an often referenced, but never seen, ‘control center’, the manual deployment of a 5×5-foot bright yellow ramp with a large blue wheelchair painted on it;
- the public declarations of the abnormal riders’ travel itinerary;
- the designated ‘handicap’ cars with ‘handicap’ seating;
- the separate debarking process;
- the separate and delayed exit from the system, etc.

All in all, a multiplicity of separate and stigmatising policies and procedures that make a spectacle of the abnormal rider: the goal at every turn is to ‘individualise the excluded; and ‘use procedures of individualisation to mark exclusion’ (Foucault, 1995, p. 199).

The internalised gaze of the disciplined rider and the system norms informing
it proves key elements in the enforcement of transit standards. The gaze is exercised as a right and a responsibility. This has been well evidenced on Chicago buses and trains where ‘disciplined’ passengers, under the authority of the internalised gaze, have been known to engage in forcible acts of coercion (e.g. verbal assaults, threats or physical removal) of disabled riders who refuse to accept separate or unequal service, and whose protests are perceived as negatively impacting system efficiency. ‘Normal’ travellers negotiate the uncertainty of this terrain by accepting that they cannot understand these spaces or the acts of exclusion committed in them. By perceiving abnormal spaces as unintelligible, moral dilemmas associated with discriminatory practices towards abnormal riders are reduced, and system norms are enforced.

In US disability communities, where 70% are unemployed, and where a significant number do not drive, access to public transportation is critical to full inclusion in community life and employment. Yet in the Chicago model of rapid rail transit, abnormal bodies, unlike their ‘normal’ counterparts, are not moved efficiently and effectively. Instead, panopticism works to control abnormal riders by cordonning them off and requiring their participation in negotiating multiple layers of socially constructed systemic barriers. Foucault might well describe the abnormal body in modern day transit spaces as a ‘prisoner in the midst of what is the freest, the openest of routes … the prisoner of the passage’ (1988, p. 11).

Articulating the Norm: Speech and Disciplinary Subjection

Denise Nepveux

In the fall term of my senior year in college, I was compelled by an academic advisor to undergo 12 sessions of speech therapy. She had noticed upon meeting me that I had a slight lisp of which I had not previously been aware. She insisted that I pursue its remedy in our university clinic as a pre-condition to my clinical training. In particular, she would not allow me to attempt my pediatric traineeship until this defect was abolished. I complied with the required intervention and completed my degree, but paradoxically abandoned my plans for the graduate-level training I would need in order to practice. My task in this essay, then, is to begin to excavate the processes of what Foucault and Butler would term my ‘subjectivation’—how, through the roles of patient, student, and patient again, I was subjected to the norms and regimes of speech pathology, how this process capitalised upon and shaped who I was as a young woman, and how, ironically, this shaping fostered my resistance to and withdrawal from the field.

For Butler, our primal longings for social existence make us into ‘exploitable kind[s] of being[s]’ (1997, p. 20). Power exploits our desire for connection, belonging, and social intelligibility by providing both a narrative trajectory for that desire and barriers to its full realisation. Having grown up with a developmentally disabled sister, I had taken pains to keep my identity firmly on the side of ‘normal’, while believing that human variation was a good and desirable thing for other people.
As a result, I subscribed to an array of normalising regimes: wearing braces on my teeth, tanning, reading fashion magazines and aerobicising.

I first became acquainted with speech pathology when, as a 17-year old summer amusement park worker, I developed a raspy voice and painful vocal cords. That therapeutic encounter enabled me to adopt a new speaking voice, and suggested to me that discipline and self-transformation were indeed within my grasp. My speech therapist became a role model for me and encouraged my newfound interest in her career path. Later, as I struggled to find a place for myself in a competitive university milieu, I continued to be immensely vulnerable to messages that personal characteristics might render me undesirable or set me apart as ‘other’. Although campus life offered many alternatives, I largely adhered to what appeared to be safe routes for my social and economic viability: pursuit of a known profession, conventional social outlets and self-normalising practices.

Preparation for a career in speech pathology was perhaps the culmination of my strivings for security through social and bodily conformity. Courses in phonetics, audiology, language acquisition and cognitive science seemed to offer a roadmap to further human improvement and the eradication of aberrancy. To help others improve and gain social intelligibility provided a dignified way of deepening my own entrenchment in the domain of the normal. In retrospect, my pursuit of this trajectory seems akin to the religious model of subjection described by Butler, following Hegel: the church (here, a profession) offers the supplicant a route from deep fears of bodily vulnerability, through self-discipline, to a sense of spiritual existence and a belief that one is enacting a ‘community of wills’ (1997, p. 52). My advisor’s ultimatum, though initially repugnant, appeared upon reflection to offer not only an opportunity for self-improvement, but a way to transform myself into a more valuable therapeutic tool. To undergo a round of articulation therapy, then, was not only consistent with my roster of self-disciplinary projects, but it played upon and enhanced my investment in a dream of meaningful contribution to an affirming professional community.

The question might now be asked as to what speech pathology had to gain from perfecting my speech. Why did the discipline concern itself with me? For Foucault, repression not only constitutes, but expands the field for regulation. The goal of disciplinary power is not actually to bring bodies closer to a normative ideal, but to give power access to bodies. Like all professions, speech pathology must foster society’s ongoing acceptance of its norms in order to perpetuate its viability and gain access to new economic niches. I would venture that it accomplishes this first in and through its own practitioners. The presence of a ‘pathological’ speech pathologist, if allowed to persist, might suggest three harmful possibilities: a practitioner incapable of self-correction (incompetent therapist), a limitation in the profession’s methods (ineffective profession), or, perhaps riskiest of all, a display of alternatives to the very norms and imperatives of the discipline.

If, on the other hand, a profession gains access to its novices’ bodies by exposing any deviance as a threat to their admission (or indeed to their personhood), it reliably produces agents of its own perpetuation. Although my speech pathology advisor took a blunt approach, my experience of subjection was not unique. Similar
processes occur widely among novices—medical students, fearing disease in themselves, begin to diagnose and label one another, and occupational therapy students are taught to critique one another’s postural ‘defects’. Fears of transgressing the boundary between observer and observed are played out among trainees, and our professional identities rest upon the tenuous resolution of these fears. A trajectory for endless fear and endless desire is thus lain. As professional purveyors of normalised existence, knowing that we narrowly have gained and retain our place, we come to enact Butler’s definition of subjection: ‘radical dependency’ masquerading as autonomy (1997, p. 83).

Desire, although exploitable, retains an ability to withdraw from attachments as part of its own preservation. In my case, withdrawal from my strivings for normalcy through a chosen profession occurred when my subjection was most acute. Only now do I associate the inexplicable grief I carried that autumn with my growing ambivalence toward speech pathology’s normative violence. Despite a concern that my 4 years of educational effort would thereby be wasted, I decided not to pursue graduate training and sought another path.

For Butler, one way in which subjection may be made vulnerable is through performative repetition, i.e. the repeated and ongoing subjection of many bodies who inevitably miss the mark in innumerable and potentially creative ways. Perhaps only by remaining subjects to an institution of power may we fulfill Butler’s hopes for the imaginative re-embodiment and reiteration of norms. I would suggest that, at a minimum, we must engage in dialogue if we wish to affect change. My early withdrawal from the field of speech pathology did nothing to challenge the profession. However, just as power incorporates what it cannot subdue, allied health professions are admitting trainees with speech ‘aberrations’ and other forms of disability in increasing numbers. In the United States, the Americans with Disabilities Act assures this possibility, if not its actuality. Professionals with disabilities hold both promise and risk to the contestation of oppressive norms of bodily form and gesture. Many, like religious converts, may outdo able-bodied peers in their discipleship. Others may suffer enough alienation that they abandon their chosen disciplines as I did. Still others may become activists within their fields. The professions have a crucial opportunity now to risk supporting and learning from these trainees and professionals, rather than merely subjecting them to normalizing regimes posing as ‘natural’ and ‘immutable’. One encouraging development is that disabled practitioner interest groups are forming within professional organisations such as the American Occupational Therapy Association. Disability scholars, activists, and professionals must support one another’s explorations and transgressions of social and institutional boundaries. In so doing, we will embolden our collective efforts to re-imagine and re-embody, and what ‘good’ form, gesture and even community can mean.

Racial Taxonomy and the Clinical Therapist

Nefertiti L. Nowell

There are many times when a clinical therapist meets a diagnosis and description before becoming acquainted with a person. A practitioner uses a chart or case notes
as a means of familiarizing oneself with diagnostic truths before the individual described can ‘taint’ the practitioner’s scientific view with factors such as personal narrative experience. Intake interviews, chart notes and other clinical paper documentation can also be used to further anchor diagnosis and behaviour reports. A clinician is taught to view an individual through the empirical taxonomy of symptomatology, to have confidence in the taxonomy and the definitive answers that it holds. One is taught to treat the classification as a pure conveyance of absolute authority. This act of understanding the state of a person through his or her classificatory diagnostic terms helps to sustain a framework within which the ‘client’ and practitioner operate.

In the Chicago Public School system I have served as a clinician and a surrogate parent to African American children who are also wards of the state. When children enter the school system they are all students—a relatively undifferentiated group in the eyes of the institution. After classes have been in session, teachers begin to assess behavior and students begin to be divided based on their observed characteristics. As a result, the student may be further separated from his classmates and placed in a special class so that his/her newly classified needs may be ‘met’ and the ‘problem’ behaviour further documented. When grouped with other students diagnosed as ADHD, for example, a further surveillance of behaviour is taken up to more definitively classify the type of ADHD a child presents. He/she may be classified as predominately inattentive, predominately hyperactive or of a combined type. This diagnosis is then documented and placed on file so others encountering the student will be aware of his defining behaviour prior to any interaction. Yet, as Foucault has argued, diagnoses are fully susceptible to the social ideologies of the period in which they are developed. ADHD has become more than just a designation of hyperactivity. In the US it has become increasingly used as the primary pathological classification of black boys.

Michael Porter (1998) argues that the American Public School system has made the words ‘Black Male’ synonymous with ‘disabled’. Porter asserts that this has been primarily accomplished by the creation of labels such as ADHD to describe Behavioral and Emotional Disorders. This racialisation of differentiation imparts particular information to those who encounter the students diagnosed in the category. The label designates black boys as sick, unable to control their own bodies and, ultimately, morally inferior. In addition, the label starts these children on a pathway of medication and medical intervention in order to support the diagnosis. Furthermore, the classification defines children in fixed terms at a time when they have not fully developed, and even their own self-definitions are ever changing and unclear. The diagnosis provides authority to practice a voyeuristic gaze into the lives of these children—and black masculinity in general—by placing them in a location called ‘ADHD’.

There are numerous unwanted repercussions to this type of differentiation. First, due to the negative positioning of disability in general, many blacks feel that disability produces a doubly stigmatised existence for black children. Secondly, civil rights movements in the US have historically sought to gain equality by distancing themselves from a biologically-based racial inferiority. This historical legacy has left
the myth of disability as synonymous with organic inferiority largely intact within black communities. As a result, black theorists may inadvertently perpetuate stigmatising beliefs about disability in an effort to analyse the racial underpinnings of pathological taxonomies. Arguments against the use of impairment labels for black children further entrench disability in a negative light. Consequently, not only is the taxonomy detrimental but further tension is produced between race and disability as mutually stigmatising social terms.

Many black theorists argue that medical labels hold no neutral truths as a result of the racial bias that informs them. Medical pathologies become a tactic used by whites to control the social space of blacks throughout their life course. For instance, Kunjufu (1995) argues that black males are targeted for destruction in our school systems so that they will not be a threat to society as adults. Over-prescribed labels such as ADHD are used as a source of control that equates black masculinity with pathology. Within this reading, the fundamental view of disability is not the focus, but rather a racist ideology inherent in the pathologisation and differentiation of black children within our current system.

These views are summed up most succinctly by Porter: ‘Every facet of American society works for the maintenance of the White supremacist system’ (1998, pp 8–9). I would argue that many disabled people feel American society also seeks to promote the status of those who lack a disability at their expense. These hierarchical inferences can be made by an investigation into the process of differentiation that both groups have been subject to; thus, black and disability communities share oppositions to the use of stigmatising language to describe their members.

Differentiation aggressively operates as though extending pathological categories will ultimately provide more accurate information. As a black woman who has operated across these systems, I understand the information and the hierarchy that labels communicate. When I am encountered, people must position themselves with respect to my blackness and my gender. With the words ‘Black Female’ comes an understood body of knowledge, assumptions, theories and beliefs about my behaviour, intelligence, and life to which my own experience cannot speak. In as much as people believe they know me when they hear ‘black female’, they also believe they know black boys when they hear ADHD, just as they know ‘disabled people’ when they hear disability.

Disability studies then, must further assess the fictive unity that clinical terminology creates. Judith Butler is well known for deconstructing an essential unity for gender in order to arrive at a more nuanced—and less universalising—gender politics. Similar ideas can be imparted to the fictive unity of the words ‘the disabled’, ‘persons with disabilities’, ‘the mentally ill’, ‘deaf’, etc. All of the supposed ‘groups’ mentioned can be called disabled, and assigned rehabilitative therapies, social treatments and educational regimes, but they are somehow different and theorised upon separately. Even though in a broad sense they are seen as a unit—the disabled—they are divided out because of their respective disabilities, severity and the societal ‘complication’ associated with each.

It will prove fruitful for disability scholars, clinicians and others in intersecting fields to theorise the gaps that our articulations represent with reference to disability
and race (as well as their intersections). In addition, theorists must pursue the tensions that our arguments create, and the comfort that we feel as long as our interests are not threatened. In that way we may understand why race has to position itself at a distance from disability and why disability must position itself against the medical model. A way must be found to critique the system that we use while we are using it. No one discipline can plead innocence, since we all begin by opposing major taxonomic categories to create our own jargon, narrative independence and an understanding of our very existence. We cannot begin at the beginning, because differentiation has been here since people have been around, and history has bequeathed us strategies for coping that can be analysed, but not entirely undone. We must begin with the here and now, by recognising the patterns and tools of taxonomy that are alive, and well in our respective domains as well as where they intersect.

**Producing ‘Normalcy’: Absence at the Core of Aberrancy**

_Michelle Jarman_

Within the last year the Cour de Cassation, France’s highest court of appeal, has handed down two controversial decisions which, if carried to their logical conclusion, threaten to legally deny people with disabilities the ‘right to life’. On November 17, 2000, the court ruled ‘in favour’ of Nicolas Perruche, a physically and cognitively disabled boy whose mother brought suit against doctors for allowing her son to be born, instead of aborted. Josette and Christian Perruche, the boy’s parents, sued doctors for failing to realize she had contracted German measles during her pregnancy: ‘Mistakes committed by the doctors and the laboratory prevented (Mrs Perruche) from exercising her choice to end the pregnancy’ (BBC News, 2000).

The court’s decision was widely denounced by disability rights supporters and medical practitioners who decried the establishment of a law granting disabled children the ‘right not to be born’ (BBC News, 2001). Some fears were realised by July of 2001 when the Cour de Cassation upheld its Perruche case decision by awarding three more families compensation for not receiving the ‘option’ of abortion during pregnancy. The children in these cases, described by the court as ‘severely disabled’, were between the ages of 9 and 11 at the time of the trial. One child has a ‘malformation of the spine’ and the other two were born with one arm. The contingent nature of defining ‘disability’, ‘severity’ and ‘abnormality’ exposes the inherent impossibility of using such terms to assess the value of human life. As one medical lawyer observed, these rulings revealed the ‘real risk of … starting a process that ends with the search for the perfect child’ (BBC News, 2001).

While the Cour de Cassation’s decisions pose troubling implications for people with disabilities in France, our purpose is to address the belief systems undergirding such rulings and the political subjectivities they invoke. Of particular interest are the problems inherent in social _ideals_, such as ‘normalcy’ and ‘health’. As the discussions of Foucault and Butler in the earlier segments of this essay indicate, a pervasive
power of privilege and exclusion is informed and enacted by such categorisations. However, this fantasy of the ‘norm’ or the ‘pure’ has no tangible core; their meanings are derived from a careful delineation of their opposites—such as ‘abnormal’ or ‘deviant’. These imposed socio-political designations position a contingent group of people in material contrast to the social fantasies of an ableist majority.

The rulings in France solidify assumptions of disability as lack by positioning disabled people in social opposition to a range of state authorised ideals. Through juridical decision-making, the lack represented by disability is sanctioned—not only as undesirable—but as illegitimate (one in need of detection and eradication). People with disabilities and advocates have resisted these imposed definitions by exposing the socially constructed nature of such valuations and by authorising contrasting disability perspectives. However, retrieval of social status is vastly more complex than a process of re-signification and reclamation. Slavoj Žižek’s discussion of stigmatised subject formation in The Sublime Object of Ideology is uniquely relevant to understanding non-disabled society’s efforts to sustain disability’s lack of access to its own less diminished social identity. Žižek argues that any society, in order to establish an ideal image of itself, will necessarily produce deviations from that ideal in an operation of definitional contrast. The more totalizing the ideal, the more lethal it becomes to inhabit its antithesis—the position of ‘pure difference’.

Zizek uses the ‘Aryan’ construction of ‘Jew’ in Nazi Germany as a primary example of the social production of identity based on ‘pure difference’. In a society attempting to define itself in terms of a racial ideal, the ‘Jew’ became a signifying container for displaced antagonisms already present in Nazi society:

[T]he basic trick of anti-Semitism is to displace social antagonism into antagonism between the sound social texture, social body, and the Jew as the force corroding it, the force of corruption. Thus it is not society itself which is ‘impossible’, based on antagonism—the source of corruption is located in a particular entity, the Jew. (Žižek, 1989, p. 125)

By defining the ‘Jew’ as corrupt, as profiteer, as seducer, immoral, dirty, etc., Aryan society constructed its own identity out of an imagined absence of such antagonisms. In effect, the signifier ‘Jew’ provided the most complete material representation of Aryan society because it established the necessary site of opposition—a carefully delineated ‘pure difference’—against which an ideological fantasy of the ‘pure society’ could be formed.

While the definition of ‘Jew’ by Nazi Germany attempted a rhetorical justification for a racial coding of biological inferiority, the construct of Aryan society’s outcast ‘Jew’ parallels our own moment’s positioning of ‘disability’. Much as the ‘Jew’ masked the essential impossibility of the Aryan ideal, disabled peoples (‘the mad’, ‘the cripple’, ‘the beggar’, ‘the freak’, ‘the crazy’—note the shared distancing determiner that characterises each formation) have been positioned across countless moments and locations as signifying containers for those disqualified from the social fantasy called ‘normal’. The recent decisions in France mark a perilous movement toward a totalizing ideology; one that threatens, in Ernesto Laclau’s and Chantal Mouffe’s terms, to suture disability identity as ‘pure lack’.
Imposing the ‘right not to be born’ upon foetuses designated as ‘disabled’ provides a mandate for the systematic medical elimination of bodily and mental variation (an ideology of eradication that often already occurs without legal sanction).

The imposition of normalcy is clearly a dangerous—even deadly—prospect for disabled populations, but how is the meaning of normalcy sustained? Much of Zizek’s theoretical work focuses on the production of meaning and its relationship to the maintenance of ideological formation. For Zizek normalcy can be theorised as a ‘nodal point’ that fixes the meaning of otherwise dynamic social entities. As such, normalcy works as an ideological suture that temporarily halts the field of sliding signifiers, which reference disability. However, we don’t come to understand ‘normalcy’ through the positive content of its own constitutive elements; we define ‘normalcy’ by the extensive network of positions that define ‘abnormalcy’—those biologies believed to deviate too dramatically from the norm. The more ‘depth’ there is to the negative contrasting term, the more ‘normalcy’ seems to stand on solid ground.

According to the ruling by the Cour de Cassation, this site of opposition is occupied by ‘disability’. As these cases demonstrate, parents then become complicit in further entrenching the stigma of difference by taking an ‘inhumane’ stance—one that winds up opposing the humanity of their own children—in an effort to assert their rights within the socially idealised domain of normalcy.

One of the most troubling issues brought up by the recent decisions in France is that the Cour de Cassation professes to be acting upon humanitarian principles (i.e. in the interest of the health and protection of its citizens). However, a close reading of these rulings makes too obvious that the quest for ‘health’ can only be attained through a legalised and systematic programme of human abortion, sterilisation and ritual sacrifice. The ruling seeks to position people with disabilities as a ‘flawed’ embodiment preventing the impossible realisation of ‘society’ as whole and complete—as a collectively healthy body made up of healthy individuals. In actuality, however, disability is a symptom of French democracy’s inability to postulate a larger field of human differences.

After looking at France’s fantasy of eradication, we are left with an interesting question: once a society is exposed to fundamental underlying antagonisms, why does it remain to resistant to change? Zizek does not believe that unmasking the void behind society’s fantasy object will necessarily produce a socially responsible reaction. He formulates ways in which social constructions of fantasy serve as a direct representation of social antagonisms: ‘... fantasy is a means for an ideology to take its own failure into account in advance’ (p. 126). In other words, fantasy is an integral part of the success of such constructions. An enjoyment lies at the heart of knowing that a society of ‘normalcy’ proves impossible—and this irrational pleasure provides the terrain for perpetuating the idea of human ‘invalids’.

Although Zizek’s social theory does not provide a comfortable way out of the impossible opposition between fantasy and ‘pure difference’, it does make clear that efforts to eradicate difference prove symptomatic of the flawed structures that undergird social systems. If we replace ‘Jew’ with ‘disability’ in the following quote, we can extrapolate important final insights:
It [disability] appears as an outward positive cause whose elimination would enable us to restore order, stability and identity. But in ‘going through the fantasy’ we must in the same move identify with the symptom: we must recognize in the properties attributed to [disability] the necessary product of our very social system; we must recognize in the ‘excesses’ attributed to [disability] the truth about ourselves. (p. 128)

In order to challenge society’s perception of disability and to promote the development of viable disability subjectivities, it is crucial to call attention to the social and political position imposed upon the category itself. The scapegoating of people with disabilities presents a threat to subjective liberty—not only to people with disabilities, but to everyone living in a society that masks its own violence in homogenous fantasies of ‘health’, ‘normalcy’ and ‘purity’.

**Conclusion: a Productive Fragmentation**

The analyses of social systems, therapeutic disciplinary ideologies, race-based diagnoses and legal rulings over ‘unviable’ life forms offered in this essay, present a glimpse into the productive heterogeneity characterising disability studies. One of the hallmarks of Laclau & Mouffe’s *Hegemony and Socialist Strategy*, is their contention that as political movements ‘become more diverse and the terrain of mass struggle more complex, ... a vanguard ... must increasingly broaden the hiatus between its own identity and that of the sectors it seeks to lead’ (1985, p. 151). The struggle for civil rights requires the construction of a totalizing rubric that gives any movement a shared nodal identity (i.e. women, gay, working class, African American). However, in constructing a unifying social formation one also invites its other—splintering coalitions that critique ‘disability’ as a universalising rubric that cannot represent the diversity of identities that comprise it.

For the theorists of political subjectivities (and implicit across the narratives and interests offered in this paper), this splintering is not unwelcome. For instance, Laclau & Mouffe theorize this necessary fracturing as the primary condition of *radical democracy* (1985, p. 182); Judith Butler argues that the non-essentialist basis of gender inevitably leads to the failure of any monolithic coalition based upon feminine sexuality from remaining coherent (1999, p. 39); Slavoj Zizek argues that desire guides the diffuse formation of ideological subjects as much as the ‘rationalism’ of any specific political program (1989, p. 99).

Disability studies and the disability movement are also undergoing similar ruptures. Intellectual disability has admonished the field’s overidentification with physical disability; a deaf community has refused to embrace disability in order to define itself as a ‘linguistic minority'; blind communities have challenged the lack of awareness governing issues of alternative formats; age-of-onset disability theorists have sought to distinguish their issues from those who acquire disabilities later in life; interests as disparate as disability art and clinical sciences have reintroduced the specificity of bodies back into the social model of disability, etc. The challenge will be to see whether disability can sustain the currency of an identity-based movement.
by embracing these fractures as constituent of a fluid and productive social formation.

Acknowledgements

Each of us is grateful for one another’s collegial input, readings, and responses. We also appreciate the contributions of other participants in the UIC Collective on Political Subjectivities: Yangling ‘Millie’ Li, Rebecca Maskos, Cal Montgomery, Sharon Smith and Sara Vogt.

NOTE

[1] The phrase ‘Chicago model of Disability’ was coined by Carol Gill to describe future possibilities for Disability Studies scholarship: ‘A stimulating recent development in disability studies is the increasingly vocal demand by many disability scholars, researchers and advocates with disabilities to restore and explore the place of impairment in the disability experience. They point out that even in an ideal society where human difference would be completely accepted and accommodated, some individuals would still experience impairment-related difficulties. Without disputing the social construction of disability, these voices are pressing for a sophisticated discovery of how impairment and functional difference contribute both to the individual experience of disability and to society’s response to disabled persons. Stated more simply, they believe that understanding disability requires a better understanding of the interaction between impairment and disability between the biological and the social’ (2000, internal document).

REFERENCES


