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Mentalism, disability rights and modern eugenics in a ‘brave new world’
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What are some of the implications of the various ways in which contemporary allopathic medicine is presumably ‘treating’ or aiming to ‘prevent’ the development of certain mental health ‘concerns’, often labeled ‘illnesses’? In this essay the co-authors adopt the position that ‘mainstream’ medicine seems to be taking some dangerous turns and that these turns have serious potential consequences for human variance and diversity. The authors believe that genetic testing and medication for bipolar disorder are problematic illustrations of the ways in which a ‘brave new world’ is now being foreshadowed and, unfortunately, will perhaps be realized in the near future. In order to frame our discussion, we incorporate close readings of literary and cinematic texts. The essay is situated by a discussion regarding ‘mentalism’ and the consumer/survivor/ex-patient rights and disability rights movements. Specific implications for the fields of social work, rehabilitation and mental health practice are discussed.

Keywords: eugenics; biomedicine; mental illness; bipolar disorder; social work; disability rights

Introduction: mentalism and disability rights in a ‘brave new world’
This essay’s authors seek to join ongoing conversations about the relationships between disability studies, mental health activism and the ethical considerations faced by practitioners in social work, rehabilitation and mental health. The authors, two Masters of Social Work students and a social worker, who is also a professor of social work at a northeastern US university, share a lifelong commitment to mental health activism. The essay presents a set of interrelated critical questions about what are often considered to be controversial topics: eugenics, euthanasia and biomedicine in the modern psychiatric age. In particular, this essay discusses genetic testing and medication for bipolar disorder (and ‘mental illnesses’ in general) as problematic illustrations of the ways in which a ‘brave new world’ is now being foreshadowed and, unfortunately, will perhaps be realized in the very near future. In order to frame our discussion, the essay incorporates close readings of a ‘classic’ literary text (Brave New World) and a contemporary cinematic text (Gattaca). Before embarking upon our analysis the essay is situated by a discussion regarding ‘mentalism’ and the consumer/survivor/ex-patient (c/s/x) rights and disability rights movements. Specific implications for the fields of social work, rehabilitation and mental health practice are discussed at the essay’s conclusion.
Disability studies writers and activists have argued that disability needs to be understood within specific socio-political contexts. Mental health advocates, including those who identify as c/s/x, have at times sought alliances with disability studies writers and activists, as well as vice versa. Peter Beresford (2000), among others, seeks linkages and perceives overlaps between the disability rights and c/s/x movements. While he affirms the similarities, Beresford likewise has commented upon the distinctions that exist between them. At times these social justice and civil liberties movements may work at cross-purposes, whether intentionally or unintentionally. For, in addition to living in an ableist world, we live in a world of mentalism, wherein individual actors, including those who identify as physically and cognitively disabled, are supposed to behave in presumably ‘normal’ and ‘rational’ ways. It could be argued, therefore, that individuals who may already be disenfranchised by virtue of being or being labeled as disabled in an ableist world have to go ‘the extra mile’ to prove that they/we are mentally and emotionally ‘fit’ to work in mainstream society and that they/we can ‘succeed’ in neo-liberal capitalism. Thus, some might say that mentalism is an issue within the mainstream societal sphere as well as within the worlds of disability rights and disability studies.

Thomas Szasz (2003) saw the contemporary mental health industry, and the pharmaceutical industry in particular, as having a central role in what he terms a ‘pharmacacy’, a political playing field whose workings are the purview of ‘The bureaucrats of the therapeutic state’ (p. 144). In an excellent discussion of this phenomenon in the UK Beresford and Wilson (2002) critiqued ‘New biogenetic approaches to mental health policy, practice and mental health service users’ and said that these approaches:

give a new spurious authority and legitimacy to a medical model, with their scientific and modernist trappings. … At the same time, they reinforce any desire or tendency to disassociate madness and distress from the social, political and economic conditions with which there are strongly evidenced associations, including poverty, war, forced migration, inequality, powerlessness and oppression.

These authors argued that:

We must also consider the role of the drug companies in relation to this issue. They already have a massive financial and philosophical investment and key role in the medicalisation of madness and distress. They can be expected to be a key player and have an increasing role in the development of biogenetic discussion, explanations and ‘treatments’. (pp. 548–9)

Importantly, mental health advocates, including c/s/x activists, and members of the disability rights movement have varied and important opinions to bring to debates about biomedicine, eugenics and euthanasia in relation to mental health politics and ‘pharmacacy’. As Wiener (2005) noted, these individuals have ‘the potential to make profound and diverse contributions to our understanding of how biomedical models influence public understandings of mental health and of disability, and, in addition, how we might intervene to produce alternative understandings’ (p. 46).

**Psychiatric medication for ‘mental illness’: the post-natal eugenics movement**

In 1932 Aldous Huxley published his most famous work, *Brave new world*. His novel details a dystopian society in which those in power attempt to eliminate all conflicts
and negative emotions though a mass drugging of the populace with a drug called ‘soma’. Huxley’s primary antagonist, Mustafa Mond (‘the controller’), gives the following speech to the protagonist, John the Savage, who challenges the established social and cultural norms:

The greatest care is taken to prevent you from loving anyone too much. There’s no such thing as a divided allegiance; you’re so conditioned that you can’t help doing what you ought to do. … And if ever, by some unlucky chance, anything unpleasant should somehow happen, why, there’s always soma to give you a holiday from the facts. And there’s always soma to calm your anger, to reconcile you to your enemies, to make you patient and long-suffering. In the past you could only accomplish these things by making a great effort after years of hard moral training. Now, you swallow two or three gramme tablets, and there you are … . (Huxley 2004, 213)

Later, Mond continued to argue with John the Savage on the virtues of a society in which soma is given to everyone:

Mond: ‘We prefer to do things comfortably’.
‘In fact’, said Mustapha Mond, ‘you’re claiming the right to be unhappy’.
‘All right then’, said the Savage defiantly. ‘I’m claiming the right to be unhappy’.
‘Not to mention the right to grow old and ugly and impotent; the right to have syphilis and cancer; the right to have too little to eat; the right to be lousy; the right to live in constant apprehension of what may happen tomorrow; the right to catch typhoid; the right to be tortured by unspeakable pains of every kind’. There was a long silence.
‘I claim them all’, said the Savage at last. (Huxley 2004, 213)

Brave new world prophesized a society in which the populace is conditioned and drugged into a numb complacency that supports the hierarchical social order. Today, it can be argued, people in the USA and elsewhere are being similarly drugged using psychiatric medications in an effort to control differences perceived as threats to the dominant (idealized) social and cultural order. While the analogy between Brave new world and contemporary US society is imperfect, there is little doubt that Americans have bought into the idea that taking mind-altering drugs is desirable. Divergences from accepted ‘normal’ behaviors or mood ranges in our society are being deemed ‘disorders’ and the carriers of said ‘abnormalities’ are being medicated to conform to dominant idea(l)s of ‘normal’. Historically, eugenics movements aimed to eliminate perceived ‘defects’ in the human species. Similarly, physicians today are taking actions to medicate ‘chemical imbalances’ and thereby eliminate ‘disabilities’ of the brain. A typical response to those in the USA with any kind of mood or behavioral ‘disability’ is to urge them to take psychotropic medications that will ‘normalize’ their perceived ‘disability’.

Between 1997 and 2006 spending on antidepressants alone rose from approximately $5.1 billion per year to $13.5 billion per year. In 2006 227 million antidepressant prescriptions were dispensed to Americans, compared with 30 million in 2002 (Barber 2008, xvi). In 2002 the top 10 pharmaceutical companies had higher profits than the other 490 Fortune 500 companies combined (Barber 2008, 22). Antipsychotic medication sales rose from 1997 to 2006 from $1.3 billion to $11.5 billion per year (Barber 2008, 8). In Ohio alone Medicaid spent $65.5 million for psychotropic
medications that were used primarily as ‘chemical restraints’ for children. Using these
drugs as ‘chemical restraints’ is an off-label use, i.e. a non-approved use. Off-label
uses of psychiatric drugs are becoming increasingly prevalent (Sharav 2005a).

The use of psychotropic medications in the USA is clearly escalating. In particular,
these medications are increasingly being prescribed to children. In 2003 the Food and
Drug Administration estimated that 11 million antidepressants were prescribed for
those less than 19 years old, a 27% increase from 2000. Between 2000 and 2003 there
was an 85% increase in the diagnosis of attention deficit hyperactivity disorder
(ADHD) in 5–9 year old children, who were consequently ‘treated’ with psychotropic
medications. Among pre-schoolers the diagnosis of ADHD went up by 45%. Sixty
percent of foster care children in Texas in 2004 were given psychotropic medications,
most of which were not approved for use in children. Two-thirds of the children in
state care in Massachusetts were on psychotropic medications in 2003 for behavior
disorders. The Wall Street Journal reported that the number of children diagnosed
with bipolar disorder rose 26% from 2002 to 2004. Children as young as four are
being diagnosed with a mental illness and treated with atypical antipsychotic
medications (Sharav 2005a). There were three times as many children deemed

Between 1992 and 2003 there was a 150% increase in diagnoses of emotional
disorders among adults. Pharmaceutical advertising and the psychiatric profession
have helped to create the image of a super-person who is not unlike Nietzsche’s
‘Übermensch’; the message conveyed is that this figure is someone whom we should
all aspire to resemble – by using medications. For almost every diagnosis there is a
mind and mood altering ‘remedy’ in pill form. Medications have become most psychi-
atrists’ primary tool (Roberts 2006, 46). Increasingly, general medical practitioners
have prescribed psychiatric medications (Horowitz and Wakefield 2007) and,
therefore, some patients need not rely as heavily on psychiatrists.

Psychiatry’s diagnostic manual, the DSM, first appeared in 1952 and included
62 diagnoses. The fourth edition, DSM IV, published in 1994, has over 300 diagnoses
(Barber 2008, 113). One can conjecture that the fifth edition, due to be published in
2012, will contain even more ‘disorders’ that mainstream health professionals will
seek to medicate. As DSM IV defines mental illness much more broadly than preced-
ing editions of the DSM, especially since the advent of the NOS (not otherwise
specified) designation, the realm of ‘acceptable’ human behavior has grown narrower
(Barber 2008). The DSM is one of the major reasons why, as social worker and author
Charles Barber stated: ‘America has swallowed it all – literally. … To say we are the
most psychiatrically medicated nation on earth is … a prodigiously absurd understate-
ment’ (Barber 2008, 21).

Many medications are indeed useful for a variety of ‘severe and persistent mental
illnesses’. However, mental health professionals, relying heavily on DSM IV, are
reminiscent of Mustafa Monds, and may be similarly surprised when the chemical
interventions that they advocate do not ‘work’ for everyone. Concurrent with their
seeming advantages (in some situations or ‘cases’), medications may be damaging to
the health of children and adults alike. Nathaniel Lehrman, a psychiatrist from Brook-
lyn’s Psychiatric Center, goes as far as to suggest that the reason electroconvulsive
therapy (ECT) has gained a newfound popularity and is being increasingly used is ‘to
hide the brain damage caused by the endless drugging upon which today’s psychiatry
is based’ (Lehrman 2001). If Dr Lehrman is correct, psychiatrists and other physicians
are doing double harm, as ECT has been proven to cause brain damage (Lehrman
Significantly, the functions and repercussions of psychotropic medications are often still not well understood.

The consequences of America’s overmedication may be viewed as the ‘afterbirth’ of the eugenics movement. Psychiatry and eugenics are becoming ever similar in both methodology and philosophy. As Sharav (2005b, 111) stated, ‘eugenics and psychiatry suffer from a common philosophical fallacy that undermines the validity of their theories and their prescriptions’. Both are rooted in ‘faith-based’ ideological assumptions – that mental and behavioral ‘problems’ are biologically determined and, therefore, can be remedied by biological interventions (Sharav 2005b, 111).

There are many parallels between psychiatry and eugenics. Both seek to ‘improve’ human behavior via unproven biological theories. Neither psychiatry nor eugenics can provide valid scientific proof, thus far, for their truth claims. Both eugenics and psychiatry are fond of screening populations in order to weed out what eugenics terms ‘defects’ and psychiatry terms ‘disorders’ (Sharav 2005b, 119). Both use flawed, subjective diagnostic tools to arrive at their assessments. Therefore, psychiatry today is, in many ways, carrying the torch of eugenic methodologies that was lighted by Francis Galton in the 19th century. While eugenacists sought to modify the human condition before birth (via selective breeding and birth control), psychiatrists seek to modify the human condition post-birth (via psychotropic medications). The result of the eugenics philosophy, if taken to an extreme, is a society in which everyone is forced to have the same, arbitrary, so-called ‘desirable’ genetic attributes. The result of psychiatric philosophy, if taken to an extreme, is a society in which even those who scarcely meet the criteria for a mental illness are pressured to ingest psychotropic medications to conform to an arbitrary societal norm (Sharav 2005b).

In the past eugenacists harmed great numbers of people because governments sanctioned their so-called treatments, providing the illusion of legitimacy to the public. The public was largely convinced by the eugenacists that laws legalizing racial segregation, sterilization and closing the nation’s borders were supported by good research from the scientific community. These laws, based on eugenic ideology, were embedded in American popular culture and in the collective American psyche (Sharav 2005b, 118). Similarly, because the public today often views psychiatric methods as the result of good research by the scientific community, psychiatry’s assertions are now embedded deeply within American popular culture. Yet, as noted, many of psychiatry’s assertions (like the assertions of eugenicists) have not been scientifically proven.

Mainstream contemporary psychiatry utilizes the state to coerce parents to allow mental health screening of their children through TeenScreen and the Texas Medication Algorithm Project (TMAP), government-sponsored programs praised in President Bush’s New Freedom Commission on Mental Health report (Sharav 2005a). Within the first three years of his presidency President Bush instructed 25 federal agencies to implement a plan that would screen America’s 52,000,000 school children and 6,000,000 school personnel for mental illness (Lenzer 2004, cited in Sharav 2005a). An Orwellian-sounding program, TeenScreen uses a national mental health questionnaire developed by psychiatrists at Columbia University as a screening tool. The program currently operates in at least 34 states in over 100 schools. In 2003 TeenScreen was used on over 14,200 teens of whom 3500 (24.6%) qualified as having a mental health problem and, probably, were considered suitable candidates for psychotropic medications. In sum, psychiatry is moving ever closer to creating a society similar to the one Huxley presented in Brave new world. Not only are the surveys and
questionnaires that are the bases of the screening subjective, the results are also interpreted subjectively, and are thus open to bias and prejudice (Sharav 2005a).

The federal government is not the only contributor to the overmedication of America. State governments are also getting in on the act. The TMAP is another government supported guide that promotes psychotropic medications. The TMAP is a drug industry-sponsored set of flow charts that guide psychiatrists and general practitioners in their selection of psychotropic medications for children. George Bush launched the TMAP in 1995 while he was still governor of Texas. Twelve states have adopted the TMAP chart. In states where the TMAP has been adopted its impact is evident. It has resulted in an overwhelming increase in the prescription of antidepressants and antipsychotics to children. It is the practice of those administering the TMAP program to prescribe antidepressants and antipsychotics – which are the most expensive medications – first (Sharav 2005a).

TeenScreen and TMAP are particularly perturbing in the face of a lack of evidence that screening programs do any good on behalf of children. The US Preventative Services Task Force evaluated the TMAP and concluded that there is no evidence that the screening instruments are valid or that they result in decreased suicides (Sharav 2005a), despite the fact that the justification for TeenScreen’s existence was that it would decrease suicides among the teenagers it served. Nevertheless, the use of antipsychotics in children, due in part to TeenScreen and the TMAP, continues to escalate.

As Sharav (2005a) stated: ‘The impact of TMAP is already evident in the skyrocketing increased prescriptions for antipsychotics, which are being prescribed widely for unapproved, off-label uses, mostly to control conduct and behavior, including ADHD’. Dr Ellen Bassuk, professor at Harvard University, is cited by Sharav as having said: ‘It’s scandalous that medications are used to subdue kids for the convenience of overworked and underpaid staff or as punishment for bad behavior’. The Texas comptroller agrees with Dr Bassuk, and added that the drugs are being used to make the children ‘more docile’; the comptroller hates the fact that ‘doctors and drug companies are pushing them to make a buck’ (Sharav 2005a). In the same text Sharav argued that ‘by numbing children with psychotropic drugs’ they are undermined in a variety of ways. A Floridian neuropsychologist who examined the Texas records under the TMAP is cited by Sharav (2005a) as having said that in prescribing medications in this set of ways to children ‘we’re taking away their future’. Sharav, head of the Alliance for Human Research Protection, suggested that the motive behind the overmedication of America is not necessarily to support the mental health of the population. Rather, she stated that the motive behind medicating youth may be to increase the numbers of lifetime consumers of psychoactive drugs in the populace (Sharav 2005a).

Whether or not one agrees with Sharav’s claims, it seems clear that moods and cognition are increasingly being medicated in order to fit arbitrary social norms. This trend is furthered by advertisements that play upon the concerns that a person may not be ‘of sound mind’ and the hope that there is an easy solution – a pill – to fix one’s presumably flawed condition. Advertisements often highlight the ‘ills’ of consumers and hold out hope for a ‘cure’ through attractive sounding medications (like ‘Abilify’) and take charge positivistic slogans (such as Wellbutrin’s ‘I’m ready to experience life’), as if what one is experiencing is somehow ‘not life’. The over-availability of these drugs normalizes their consumption, makes consuming them attractive and may even make some people believe that they can live without ever experiencing ‘negative’ emotions or behaving ‘inappropriately’ (Barber 2008).
Some truly need these medications and are helped by them. For others, however, fear of being labeled as emotionally or behaviorally disabled necessitates the inappropriate ingestion of these very powerful and barely understood medications. It may not be long before we are all told that we need these medications. TeenScreen could become AdultScreen, and Huxley’s resistant character, ‘John the Savage’, could become an American reality. If the trend continues it is conceivable that, in the future, none of us may have ‘the right’ to feel even a moment of normal sadness or behave ‘inappropriately’ in the eyes of (the dominant) society.

Psychiatric and medical doctors, along with social workers and other practitioners, are given enormous responsibility by American society and wield a great deal of control over people’s lives. These individuals are, therefore, obligated to consider diagnostic assessments and other interventions carefully. It is important to remember that sadness does not always need to be diagnosed as a form of depression. Being ‘neurotic’ is not always a sign of ‘psychosis’ or a ‘personality disorder’, being superstitious is not always a sign of ‘obsessive compulsive disorder’ and being energetic and excited are not always signs of ‘mania’. Variations from the arbitrary ‘norms’ of human behavior, or mood, do not always need to be medicated.

As we move ‘forward’ in scientific progress we must not move ‘backward’ by not respecting disability and other forms of diversity. Society’s members might aim to refrain from pressuring individuals to conform to arbitrary standards of behavior and not urge everyone to have a static, ever complacent mood. Instead, we might respect those who, like John the Savage, are ‘claiming the right to be unhappy’, without any shame or stigma attached. Behavioral and emotional variance is part of human life; joys and woes must be honored simultaneously, without romanticizing either. And, again, there are some individuals who may indeed need psychotropic medications in order to survive. However, if we continue down the pharmaceutical path that we are on we may be setting the stage for a non-fictional army of ‘Mustafa Monds’ to march in, pushing ‘soma’ in the form of thousands of pharmaceuticals for everyone.

**Genetic testing for ‘mental illness’: eugenics as pre-natal euthanasia**

Despite massive advances in the field of genetic research, there is no pre-natal test for bipolar disorder (Winstead 2000). There is, however, great interest in developing one. Johns Hopkins Mood Disorders Center, in conjunction with the National Alliance on Mental Illness (NAMI), has created a ‘user friendly’ database of genetic information taken from 5000 bipolar phenotypes that is accessible to researchers interested in ‘bioinformoocics’ (http://www.hopkinsmedicine.org/Psychiatry/moods/research/bioinformoocics/).

While there is evidence suggesting that bipolar and other mood disorders have genetic components, many researchers agree that environmental and cultural factors play a significant part in whether or not a person develops a mood disorder (Lock 2005; McGuffin and Katz 1989; Sullivan, Neale, and Kendler 2000). Also, current genetic knowledge holds that mood disorders are irreducible to a single genetic locus, making genetic tests akin to ‘fortune telling’ (Lock 2005). Personal choices and actions can alter one’s chances of developing conditions to which one is (deemed) predisposed (Wickelgren 2004). The existence of human agency and the human spirit – the (relative) power(s) to make personal decisions and the drive to persist in the face of adversity – also render genetic testing on something as subjective as ‘mood disorders’ extremely problematic.
Popular films are powerful forces for disseminating social and cultural discourses, and they form the basis of popular knowledge and attitudes as well as help to shape perceptions of what is ‘normal’. In Andrew Niccol’s film *Gattaca* (1997), as in *Brave new world*, there are characters that defy the dominant cultural logic of the social system. In *Gattaca* people are no less conditioned than in *Brave new world*, and while there are some differences in methodology, the apparatuses of power seeking to build and perpetuate themselves are very much the same. In *Brave new world* people’s physical and mental traits are determined/ altered by the introduction of different external forces: temperature, chemicals, motion, psychological conditioning and drugs. In *Gattaca* it is internal qua genetic forces that are used to produce certain idealized humans.

*Gattaca* raises issues related to genetic engineering, pre- and post-natal genetic detection and selection and questions the validity of biological determinism. *Gattaca* is an epic tale of a man who beats the odds in a world in which people are systematically discriminated against based on their genetic profiles (Jeffreys 2001). People are labeled ‘Valid’ or ‘In-Valid’ if they are genetically engineered or conceived ‘the old-fashioned way’, respectively. The film’s protagonist, Vincent, is still wet with birth fluids when a machine first analyzes his DNA. The results are read aloud by a female hospital worker, whose tone and facial expressions mirror the tragic news: ‘depression 42% … heart condition 99% … life expectancy 30.2 years’. His parents are faced with the knowledge that their son will be an invalid ‘In-Valid’: a sub-par human and second class citizen. Not wanting to take the risk again, Vincent’s parents have their next child genetically engineered. The geneticist/salesman urges the couple to accept the clinic’s screening out of physical and behavioral traits when they question the extent of the tinkering, implying that it is the most correct moral and ethical choice that they can make as parents. The genetic profile of the second son ‘earned’ him his father’s name, Anton, a name that had been denied to the imperfect Vincent.

Genetic knowledge has the potential to affect the way one is treated by society and by one’s family, which would also certainly contribute to how one views oneself. The internalization of dominant social and cultural discourses around genetics and ‘mood disorders’ may shape our thoughts and behaviors, but, at least for some, there is always the possibility of questioning and dissent. Vincent will not allow anyone to tell him what he can or cannot do because he believes in the possibility of wellness (over his chances of susceptibility) and, more vitally, in his own agency and personal freedom. He educates himself in space navigation and pushes his (physical) limits, but knows that he cannot get into the space program at Gattaca until he becomes a ‘de-gene-erate’. Vincent eventually ‘borrows’ the genetic identity of Jerome Eugene Morrow, a formerly ‘Valid’ athlete who became a wheelchair user after being hit by a car.

Jeffreys (2001) notes how Jerome’s demeanor and attitude to Vincent change from superior to submissive as he is reduced to a source of DNA samples for Vincent’s consumption. The night before he gives up his identity as Jerome to Vincent he takes on a new primary social identity – his middle name, ‘Eugene’ (‘good genes’) – signifying his identification as a body deemed useless by society. Jerome, however, had been reduced to his genes long before he started harvesting bits of himself. Vincent, in a voiceover, observes that Jerome ‘suffered under the burden of [genetic] perfection’. Throughout the film Jerome reveals his sense of failure by questioning Vincent’s ability to be ‘Jerome’ when Jerome – the bearer of the genes – never got better than second place in swimming competitions. Jerome’s need
to use a wheelchair resulted from a botched suicide attempt he confesses to Vincent one drunken night, saying: ‘I couldn’t even get that right’. On the morning Vincent is to leave for Titan Eugene shows him a massive stockpile of bodily traces, ‘so Jerome will always be here when you need him’. Eugene incinerates himself, silver medal in hand, as Vincent ascends, literally, to the stars. In the end, the relative resilience of Vincent and Jerome and the choices they (are able to) make result in outcomes that oppose what genetic testing and social expectation said they should be.

*Gattaca* touches upon (re)current fears that people will be denied equal access to education, employment and health care (including insurance coverage) if their genetic profiles are less than stellar. Set in ‘the not-so-distant future’, elaborate systems of detection and surveillance operate to maintain the social order in *Gattaca*, via methods already in use by medical and governmental institutions that aim to mark or verify the identity of (potential) social and/or physical ‘deviants’. Some geneticists predict that genetic risk profiles will be developed by 2025 (Wickelgren 2004) and that ‘patients will [likely] be made aware of their genomic profiles as part of basic clinical care’ (Brice 2004, cited in Lock 2005). In one study over 75% of participants said that they would want genetic information to be made available to their doctor but would not want this information to be revealed to insurance companies (Trippitelli et al. 1998). The fact that genetic discrimination is a legitimate concern is underscored by the recent passage of the *Genetic information nondiscrimination act* (H.R. 493), making it illegal for employers and insurance companies to use genetic information to determine eligibility for employment or health coverage or to set premiums (http://thomas.loc.gov/). However, as represented in *Gattaca*, there are ways around the law and discrimination can begin before birth.

Kay Redfield Jamison, who described her personal experience of having bipolar disorder in *An unquiet mind* (Jamison 1997), co-authored a study designed to measure the attitudes of bipolar patients and their spouses to genetic testing for bipolar disorder and childbearing (Trippitelli et al. 1998; Winstead 2000). This study, despite its limited external validity (n = 90), raises issues of considerable interest, considering the continued research into the genetics of ‘mental illness’ and potential for pre-natal screening. Here, the issue of (personal) choice in aborting a mentally or emotionally ‘defective’ fetus looms heavily and, while it lies far beyond the scope of this paper, should be taken up in future work.

In the Trippitelli et al. (1998, 902) study about 41% of respondents said that fetuses should be tested for the bipolar disorder, while 55% of patients and 65% of their spouses said they would definitely or probably not abort a fetus that tested positive for bipolar disorder, implying that more than 35–45% would at least consider aborting a ‘bipolar’ fetus, even if they ultimately chose not to terminate the pregnancy. Interestingly, only about a quarter of respondents said that they would abort a fetus ‘destined’ to develop an incurable, painful disease at age 40 (Trippitelli et al. 902). These findings suggest that more people may opt to terminate a pregnancy due to mental illness than physical illness. In another study almost half the respondents (mental health consumers and providers) said they would abort a fetus that would definitely develop bipolar disorder; mental health consumers were the least likely to abort (Smith et al. 1996). Factors such as age of onset, type, duration and severity of the physical or mental ‘defect’ may partially explain these results, but such explanations are insufficient to reach a deeper understanding of the meaning of ‘mental disorders’ as they (are diagnosed to) exist today.
In the USA prospective parents can choose up to 14 genetic tests (with over 100 available) to detect ‘life-threatening ailments’ in their embryo (Wickelgren 2004, 10). Wickelgren (2004) quoted Kathy Hudson, the director of the Genetics and Public Policy Center at Johns Hopkins University, who voiced an important connection between genetic knowledge and parenting: ‘if a technology is available that allows you to pick the best embryo – you could feel like an irresponsible parent [like Vincent’s parents] if you don’t do that’ (p. 11). If fetuses are screened (and destroyed) with the stated intent of alleviating suffering and building a stronger, more robust social body, then eugenics, in one of its modern forms – pre-natal genetic testing for ‘mental disorders’ – could be considered a form of euthanasia. Having genetic knowledge may lead a person to fear their genes, feel worthless or inferior and, if there is a child involved, blame their partner or themselves if something goes ‘wrong’ in the ‘normal’ development of their child. Other perceived risks associated with genetic knowledge include parents’ concerns about the possibility of transmission and their child’s well-being, fearing that all of their actions and moods will (only) be seen as manifestations of the ‘disorder’ and being discouraged from reaching their goals (Trippitelli et al. 1998).

Although Trippitelli et al. report ‘a majority’ of participants would probably not be deterred from having children if they knew they were genetic carriers for bipolar disorder, this majority is slim: 55% of patients and 57.5% of spouses (Trippitelli et al. 1998, 902). In this case preventative birth control may be seen as another form of weeding out potential ‘undesirables’. Presumably, the erasure of physically and/or emotionally painful ‘disorders’ would result in a higher quality of (interpersonal) life for individuals and their families. Society would not have to (re)structure itself to ensure that the ‘special needs’ of ‘disabled’ people were met and their rights respected. We all carry so-called ‘flaws’ in our genetic code, but who or what should (ever) determine who has the right to exist or not based upon the possibility that someone may be susceptible to a given ‘disorder’? This is a crucial question to consider when addressing the relationships between mentalism, disability rights and modern eugenics.

Implications for social work, rehabilitation, mental health practice and activism
Respecting the dignity of persons with disabilities, and social workers’ ethical obligation to ‘do no harm’, certainly interface in complex ways with the controversial debates surrounding pre- and post-natal eugenics interventions, including, but not limited to, the prevention and ‘treatment’ of bipolar disorder. Some would argue that fetuses and yet to be born children have certain rights, as do fully fledged adults. While it is beyond the purview of our analysis to enter fully into a debate about abortion rights (as noted above), it is certainly important to consider how the decisions that parents may make concerning fetuses and yet to be born children are crucial and merit the attention of social workers and others working in the fields of rehabilitation and mental health. Activists of various viewpoints will surely continue to argue about what is in the best interest of families and children, in the context of a larger set of societal frameworks.

It has been remarked (both sympathetically and critically) that social workers are at times complicit with the very systems of power that we seek to disrupt. Moreover, it is understandably difficult for many social workers to work within and despite ‘the system’, simultaneously. Social workers, necessarily, are strategists who must
manipulate the status quo in the structures within which we find ourselves. Olson (2007) described how social work can be a fraught terrain of ‘discourses in conflict’. He asserted that rather than giving primacy to professionalization, social workers must work primarily towards social justice. Olson argued that this often happens in reverse, wherein the ‘social justice project’ serves the ‘professional project’, instead of the other way around.

The National Association of Social Workers (NASW) in the USA has a code of ethics (NASW 1999) that requires social workers to advocate social change. According to the NASW advocacy is ‘the heart’ of the profession. Certainly, it can, at times, be quite challenging for social workers to know how to advocate for what, for whom and under what circumstances, and to do so without condescension or patronizing the clients, constituents and communities that we aim to serve. We, as co-authors, believe that any kind of presumed ‘treatment’ for or of bipolar disorder (or, for that matter, any ‘mental illness’), ‘handled’ very differently in vitro versus post-birth, needs much more discussion within the mental health field, since these subjects touch upon a host of ethical and advocacy considerations that must be negotiated with great care, and in consultation with disability rights activists and other social actors living within a ‘brave new world’.

References


