Journeys to Embracing Down Syndrome:

A Critical Analysis of Disability Narratives in Popular Culture

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I hereby recognize and pledge to fulfill my responsibilities as defined in the Honor Code and to maintain the integrity of both myself and the College community as a whole.

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Pledge

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Table of Contents

Introduction .....pg. 1
Exploration of the Context and Literature on Down Syndrome .....pg. 4
Theoretical Framework .....pg. 17
Analysis .....pg. 19
Conclusion .....pg. 32
References .....pg. 34

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Introduction

The increasing presence of disability in modern life has started new conversations and created many changes in academia and society as a whole. While progress has been made there is still a shocking absence of serious discussion and study of disability. Throughout my academic career my eyes have been opened to many new differences and inequalities. There has always been some presence of disability in my life, and these experiences had shaped my views of cognitive and physical disability in a positive way. Viewing the documentary Monica and David as a sophomore renewed a passion I had for studying and assisting in the improvement of health, well-being, and inclusion of people with Down syndrome.

The four dimensions of global health intimately intersect any discussion of Down syndrome. The dimension of sciences and the environment has a surface link with the understanding of what Down syndrome is and the clinical importance of the condition. However, there is a more important exploration of this dimension in the science of critical analysis. Critical inquiry of how people experience and express their experiences with illness and disability provides potential for greater understanding how the scientific processes interact with the natural and built environments to produce human health outcomes. Ethics and Social Responsibility is deeply explored in the inquiries of increased longevity of people with special needs, but also in the inquiry of how society discusses and represents these people and their families. Moral decisions and problems of political and social justice surrounding Down syndrome are abundant in the private and public sphere. The production of health resulting from the different valuation of people with disability of any sort requires critical inquiry, like this essay will attempt to do. Power and economics intersect in any conversation of Down syndrome because issues of

allocation of resources like health care insurance and availability of prenatal testing, other medical procedures, as well as any supportive care for a child with Down syndrome. Finally the dimension of cultures and society is of clear importance to this project as it makes serious inquiry into the functioning and structures of culture and society and how they do or do not favor certain norms.

Down syndrome is a condition caused by a chromosomal abnormality of the twenty-first chromosome that happens at conception. Down syndrome is sometimes referred to as Trisomy 21 because of an extra 21st chromosome in a egg or sperm cell. As the pregnancy continues the fetus will have an extra twenty-first chromosome (Sherman, Allen, Bean, and Freeman, 2007). This extra genetic information is the condition known as Down syndrome and has a distinct grouping of traits. A condition that was presumably Down syndrome has been documented as early as 1838, but only received is moniker after a study conducted by John L. Down in 1866 (Desai, 1997).

Almost all cases of Down syndrome result from extra material in the maternal reproductive cells, but there is little research to answer why this is so. However, there is strong evidence that risk of Down syndrome increases with maternal age (Sherman et al., 2007). Despite it being 5 times more likely that mothers of advanced age to have a child with Down syndrome, almost eighty percent of children with Down syndrome are born to mothers under the age of 35 due to the higher fertility of young women (Snijders, Sundberg, Holzgreve, Henry, and Nicolaides, 1999). The majority of women become pregnant before the age of 35 tilting the distribution of births of children with Down syndrome towards the group of lower risk.

There are other factors that contribute to the risk of having an infant with Down syndrome. Exposure to or use of oral contraceptives increases the risk of a baby having Down syndrome in older mothers. Regardless of age, exposure to smokeless chewing tobacco also increases risk of Down syndrome (Ghosh et al., 2011). There are more males with Down syndrome than females (Shin et al., 2009). People with Down syndrome have distinct physical characteristics, but each person has a unique expression of these traits. These include: floppy or rag doll like low muscle tone, flat facial features, almond shaped eyes, protruding tongue, unusual high and narrow roof of the mouth, small ears, short neck, epicanthic folds or fold of skin over the inner corner of the eye, narrowing of the first part of the small intestine, a single deep crease across the palm, short finger and toes, unusually small heads, a short flat head, broad short hands, a wide gap between the first and second toes, cardiac anomalies, and short stature (Domino, 2007).

Down syndrome is a condition that is present globally. However, there are many more white people with Down syndrome than black individuals (Shin et al., 2009). Asian countries like Singapore also experience Down syndrome with approximately 9 of every 10,000 live births in 1998 being a child with Down syndrome (Lai et al., 2002). These rates are lower than those seen in the United Kingdom in the era where approximately 17 of every 10,000 live births were children with Down syndrome (Irving et al., 2008). Since 1980 Europe has seen a higher rate of infants with Down syndrome being born (Dolk et al., 2005).

In addition to an increase of live births, the lifespan for people with Down syndrome has improved greatly, despite the many health challenges that accompany the

condition. In 1940 the life expectancy for someone with Down syndrome was just twelve years, it has reach around sixty years in 2007(Bittles, Bower, Hussain, and Glasson, 2007).

The practice of family or home care for people with Down syndrome is a markedly recent development. The de-institutionalization of children with Down syndrome and other mental disabilities and disorders began in 1963 when John F. Kennedy signed the Community Mental Health Act. As recent as 1971, even after de-institutionalization, treatment of Down syndrome was majorly focused on prevention of the condition. Stein and Susser suggested that maternal age was a major concern and preventive treatment was key for a "problem […] ripe for attack" (Stein and Susser, 1971).

This increase in live births and longevity is in stark contrast with intensifying screening and selective termination of fetuses with Down syndrome. Prenatal screening for Down syndrome was first available in the early 1970's. With the development of more minimally invasive tests that carry limited to no risk for both mother and fetus, medical professionals and scholars of genetics suggest that all women should be offered screening for trisomy 21 (Khalil and Pandya, 2005).

Exploration of the Context and Literature on Down Syndrome

There are many facets of the public discourse on Down syndrome. I will use this literature review to clarify the current state of understanding on illness/disability narrative, narrative analysis, and how it relates to Down syndrome. There is a large body of scholarly work devoted to the examination of how Down syndrome relates to the ethical issues raised by reproductive choice. The tension created by the presence of

prenatal testing is extremely pertinent when discussing Down syndrome because the disability caused by having Down syndrome is far more variable and often a more positive outcome than other conditions that are also prevalently tested for. Selective termination rates among mothers who receive a positive result on Down syndrome screening tests are estimated at 60% to 90% and higher (Natoli et al. 2012). Studies in the 1970's found that "a majority of physicians recommending against relatively simple surgery for life-threatening conditions in infants with Down syndrome" (Dresser, 2009:8).

Sequenom Inc. introduced a new DNA-based screening test for Down syndrome, MaterniT21, which has a reported 99.1% and 99.9% sensitivity and specificity respectively. This test provides diagnostic accuracy earlier in the pregnancy and carries no risk of miscarriage like its predecessors, CVS and amniocentesis (Kaposy, 2013). The accuracy, simplicity of administration, and decreased risk of miscarriage of the MaterniT21 test addresses many issues woman may have had for previously opting to forgo prenatal screening. MaterniT21 can be administered much earlier in pregnancy compared to previous screening methods, which means abortions within the first trimester become a possibility for mothers who receive a positive test result. The first trimester administration and the resolution of risks provided by the MaterniT21 test will likely increase in prenatal screening leading to an increase in selective termination of fetuses with Down syndrome (Kaposy, 2013).

The expressed objection of the community of people with Down syndrome and their families and caregivers is that "prenatal testing and termination of fetuses with disabilities express negative or offensive messages about people living with disabilities"

(Kaposy, 2013). A strong bias against people with Down syndrome provides explanation of high rates of selective termination thus demonstrating the harm caused by the bias. The high rates of termination are consequential of this bias, not the cause, however we can still object to this because they are actions motivated by a harmful bias (Kaposy, 2013). A 2007 study of mothers in the Netherlands who chose to selectively terminate fetuses with Down syndrome broke down the motivations of their decisions into two groups. The first group was motivations of beliefs, fears, and desires mothers had about themselves and other family member (Korenromp et al. 2007). Over 60% of the mothers responded with the following:

- they considered the burden of having a child with Down syndrome too great for their other children;
- they considered the burden too heavy for themselves;
- they did not want a disabled child;
- they thought they would become unhappy with having this child

The second grouping of motivations were related to the prospective child with Down syndrome, and in this grouping over 80% of the women stated that:

- they believed that the child would never be able to function independently;
- they considered the abnormality too severe;
- they considered the burden for the child himself/herself too heavy;
- they worried about the care of the child after their own death.

Most people would openly admit to having a bias against people with Down syndrome, however these responses show that the bias exists under the seemingly unbiased individual interpretations of their attitudes (Kaposy, 2013). This bias was a clear presence in 2008 when pro-choice, pro-life, and disability advocates joined in support of the Prenatally and Postnatally Diagnosed Awareness Act (Dresser, 2009). The law would

aim at "producing and distributing information about prenatally and postnatally diagnosed conditions" like Down syndrome (Dresser, 2009:7).

The statement "I did not want a disabled child" expresses a direct rejection of the prospective child solely on the presence of disability. In this way "awareness of the single stigmatized trait of disability makes prospective parents unhappy with a previously wanted pregnancy" (Kaposy, 2013). The biased view of the child being an unbearable burden on the mother and her older children is one half of a dangerous dichotomy of the public discourse on Down syndrome. With the 2007 recommendation that all pregnant women, regardless of age, undergo screening "it is essential that prospective parents be given accurate and balanced information" about Down syndrome (Dresser, 2009:7). The belief that children with Down syndrome will be a burden that negatively affects the family unit is high among mothers who chose to terminate after a prenatal diagnosis, but the positive response of parents who have children with Down syndrome is even higher (Kaposy, 2013). Most women among one group of mothers who continued their pregnancy reported that their obstetrician did not provide enough accurate information about Down syndrome or contacts to parents of children with Down syndrome (Dresser, 2009).

Some people argue that accusing prospective parents from making decisions motivated by a bias against people with Down syndrome to be unfair, and that their decision to terminate should not be simplified into one issue. This would require a look at the empirical studies and see the woman and her partner deciding in simple accordance with what they perceive to be the best possible outcome for their family as a whole. This first would require there to not be a bias against people with Down syndrome in today's

public discourse. However, the regular appearance of jokes centered on making fun of people with cognitive disability, and the extensive use of the word “retard” clearly demonstrate the bias against people with Down syndrome in todays public discourse (Kaposy, 2013). Derogatory material so harshly targeted at racial or ethnic groups is met with a majority outcry against it, but it is not so when the target of this harsh humor is people with cognitive disabilities. Narratives about people with Down syndrome were largely absent from the United States and other countries cultural artifacts. This first appearance of a person with Down syndrome did not occur until the premier of Life Goes on in1989 on television, and still is a rarity today. Other media like novels, books, news articles, movies, fashion, magazines, poetry, and music have also been slow to produce texts by or about people with Down syndrome. This bias remains present even with increasing publicity of narratives by parents of people with Down syndrome and people with Down syndrome. The continual diminution of adults into children showed in Sarah Palin’s, Republican representative and mother of a son with Down syndrome, approaches to disability in the public discourse compress adults with disability into the narrowly imagined framework of a child with disability (Cooley, 2011) allowing the continuation of biased beliefs.

If there were bias against people with Down syndrome then the second factor that could make this argument true would be that this bias does not impact mothers in the decision to carry, give birth, and parent a child with a stigmatized trait like Down syndrome (Kaposy, 2013). This argument is not a universal truth, but is effective in demonstrating how bias against people with Down syndrome influences population level trends in high rates of selective termination.

The routinization of prenatal screening tests could make it even more difficult for able-bodied individuals to see and understand the attitudes of bias against people with Down syndrome that impacts decisions made about selective termination (Kaposy, 2013). The simplicity, accuracy, and endorsement of the test by medical health professions will likely zoom along a process of normalization that will blind the public discourse to the reasons why objections can and should be made against the testing (Kaposy, 2013). The possibility of prenatal testing for severe disability ought to be available to all women calls up a value judgment that needs to be addressed critically. The presence, policies, and practices of prenatal testing aside, it is important to resist routinization and normalization as they prevent any critical examinations of the topic (Kaposy, 2013). Without the questioning and expositions of complacent attitudes towards routine and normalized prenatal testing we cannot challenge the hidden biases against people with Down syndrome.

Illness narratives are stories written or told by people, or of their relatives, experiencing an disease or condition and how living with this illness effects the their lives and relationships. Illness narrative has existed for a long time, and just like any form of storytelling it has evolved and grown into an integral part of our cultures and societies. The illness narrative operates to benefit us in many ways. Illness narratives can act as a source of sense-making for the teller and the listeners (Sharf and Vanderford, 2007). The act of sharing the teller's perspective of the events they have experienced can in a way help them delineate events and decode experiences that before made no sense to them. The narrative also allows the opportunity for the listeners to attempt to make sense of their lived experiences and how or if they relate or are changed by the narrative. The

temporal distancing of the events and "the "telling" of it in retrospect" (Sharf and Vanderford, 2007:17) is important in the development of meaning through the narrative.

Narratives can also provide opportunities for asserting control over a situation and transforming identities (Sharf and Vanderford, 2007). Illness and disability are often centered around a medical diagnosis and distinct categorization. These events remove the individual from active participation in their life, and narrative "puts the "I" back into a person's understanding of his or her life" (Sharf and Vanderford, 2007:21). The experiences with illness or disability told through narrative allow authors to shape or "reshape their identities, either in functional, enabling ways, or [in a way to emphasize] loss, trauma, or impairment" (Sharf and Vanderford, 2007:21). Identity is complex and these narrative process is one way individuals to express many facets of their identity (Sharf and Vanderford, 2007:23). These important facets of storytelling provide a purpose in understanding and public discourse that "illustrate the extent and proximity of the problem in a way that generalized statistics cannot" (Sharf and Vanderford, 2007:28).

Life writing is imbued in the current moments of culture both in the United States and the United Kingdom (Couser, 2011). In April 2002 Lorrain Adams made a case for the recognition of the between authors of personal narratives. In her piece she dubbed one group *somebody* memoirs and the other *nobody* memoirs. The authors of *somebody* memoirs are known before the pieces publication, while the authors of the *nobody* narratives are known through the publication of their narratives (Adams, 2008). The early 2000's saw a boom in these *nobody* memoirs and these are distinctly different from historically typical narratives of people not widely known to the public. These nobody memoirs have become some body narratives that put the body and bodily experience at

the forefront of the narrative. There is excitement that in this moment somatic anomalies are becoming accepted facets of a person, even embraced. However, the public presence of mostly idiosyncratic and existential type narratives by relatively affluent authors prevents awareness for the challenges of the disability of less privileged people (Couser, 2011). Lastly, an important development in disability narrative is what Couser calls the "me-too-memior". This type of narrative approaches the story as means of telling the social, cultural, legal, and architectural obstacles to differently abled people – "the added penalty that societies impose on those whose bodies are significantly atypical" (Couser, 2011: 232). The authors of these narratives draw a line between impairment and disability, and they have a clear line of development of a disabled identity.

The memoir may be the most visible form of life writing at present time, but it is by no means the only form. Most everyone does some type of life writing regularly, and they do not have to be purely literary forms like the memoir (Couser, 2011). Today we push to continue the work and expansion of disability in life writing by exploring the topic of disability in ways that may have been forgotten or under-surveyed (Couser, 2011). In many ways life writing explores and publicizes a personal life, but some believe that there ought to be an embracing of impersonal life. An impersonal life can be understood as a theoretical 'will to live' in each individual akin to the 'will to power' discussed by Nietzsche (Overboe, 2009).

In disability studies, like feminist, queer, and other civil rights movements and studies, each individual validates their identity and politics based upon their disabilities. Personal narratives in Disability studies are employed as counters to the hegemonic view that privileges able bodies (Overboe, 2009). The lives being lived by these storytellers are

often prejudged to a value based on the presence of self-reflexive cognition, intent, or agency. “Life narrative [...] comprehends all sorts of records of [the storytellers] lives” (Couser, 2011:234). We see disability entering many forms and genres as self-representation and exploitation (Couser, 2011). However, Overboe argues that this limited view of life fails to affirm all disabled lives. There is in narrative and in the present time a life presence that continues to flow form impersonal existence at birth to a time now where it coexists with the conscious self (Overboe, 2009). The narrative of overcoming disability may be warm and fuzzy and even inspiring, but can often creates a dangerous mindset among the public that all differently abled people are capable of overcoming their disability. In this way “the belief in the ability of people to overcome their disability affirms the lived experience of a few disabled people but invalidates the lived experience of the majority who cannot meet such expectations” (Overboe, 2009: 245). Another way to approach disability narratives is the affirmation of the supposed impairment. This choice would no longer embrace optimization and normalization as the golden ideal and to “ affirm fate and avoid a life of *ressentiment*: to find joy in the fate of the vitalism of what many perceive to be impairment” (Overboe, 2009: 246).

To affirm this impersonal life or impairment we must also recognize different alignments of the body in relation to impairment. Contemporary political and theoretical debate put the body in the center of impairment/disability, however the social model pushes it to the side (Hughes and Paterson, 1997). This social model of disability proposes that the separation of body and culture or impairment and disability is indefensible. The subject created by the separation of impairment and disability is an uneasy presence in the contemporary moment calling for the need to internally critique.

Hughes and Paterson argue that there is a not a need for the supersession of the social model, but instead a need for expansion that includes an embodied notion of disability. The social model of disability critiques the medical model of disability however still "concedes the body to medicine and understand impairment in terms of medical discourse" (Hughes and Paterson, 1997: 326). Instead of relinquishing the physicality of the body the social model establishes the body as a part of history, culture, and meaning (Hughes and Paterson, 1997). At the start of the 1980's the field of sociology became especially interested in the body, but at the same time the sociological field of disability studies seemed to discard the body. The sociology of bodies began to recognize the unalienable connectedness between social organizations and the bodiliness of their human actors, but the social model of the disability at that time threw it aside (Hughes and Paterson, 1997). These changes expanded above Cartesian sentiments and anti-foundationalism brought contemporary thought towards a relativist and nihilistic image of the mortality of the body. This dive brought into the light the body as a social issue; "the body became problematic" (Hughes and Paterson, 1997: 327). Foucault coined it as the bodies acquisition of a history, but at the same time the world of disability studies was trapped in the prominence of medical and bio-psychological thought (Hughes and Paterson, 1997). Impairment was thought of only in terms of difficulties in living as the consequence of dysfunctional bodies. Later in the 80's the social model of disability rose up and overthrew the medical. In this view it was no longer the physical dysfunction that prevented people from participation in social structures, but the source of impairment was the social system that created barriers to inclusion (Hughes and Paterson, 1997). Now in the social model of disability the body is consigned to an invisible space where it is not

mentioned. The body is solely defined in biological terms without history so that it becomes an eternal ontological foundation with no meaning.

Though it may appear that the social and biomedical model lie in stark contrast, they converge on the body in a powerful meaningful way. Both of these models treat the body as a pre-social stable physical object that is distinct and separate from the self. The biomedical definition of impairment is that of a faulty machine, and here the social model agrees. The separation of mind and body is mirrored in the social models separation of impairment and disability. This radical model suggests a disembodied subject within the field of disability studies (Hughes and Paterson, 1997). This separation distinctly removes biology from discourse of disability and places all of the biologization into impairment. This distinctions creates binary oppositions that make up distinctly defined theoretical spaces. Hughes and Paterson demonstrated this with the binary couples below (Hughes and Patterson, 1997: 330):

The biological	The social
Impairement	Disability
The body	Society
Medicine	Politics
Therapy	Emancipation
Pain	Oppression
The medical model	The social model

Scholarly inquiry into the way narratives work to represent disability are crucial since narrative plays such a large role in the study of disability. There are a variety of

ways to analyze narratives, and it is important to understand the philosophy and principles of narrative as distinct from the methods of narrative. The decision on the method of narrative analysis must be informed by the commitment or non-commitment to philosophical assumptions and principles of narrative. There is no 'best way' to conduct analysis of narratives, and neither the analyst or storyteller are more valued. It is important also to not privilege the 'whats' or the 'hows' of narrative because both are vital parts of narrative and give rise to particular strengths and weaknesses (Smith and Sparkes, 2008). We must be wary of analysis that zeros in on the hows of narratives at the expense of the whats, but by no means does a single researcher have to thoroughly focus on both the "whats" and the "hows". Gubrium and Holestein suggest the use of analytical bracketing to move back and forth between "whats" and "hows" of narrative analysis to focus from "discursive practice to discourses-in-practice" (Smith and Sparkes, 2008).

Understanding how the narrative functions is one aspect of critical inquiry, but in the study of disability there must be an additional inquiry. In addition to the first there must be an inquiry into which narratives are discussed and how they are discussed. The publicity of narrative and representation of those with cognitive disability has long held the truth to be that from awareness comes progress and reform. However, there are recent representations of cognitively disabled people that halt the realization of policy changes and work against rights and agency of the people they are intended to help. Reed Cooley exemplifies this argument through the representation of Sarah Palin's son with Down syndrome, Trig Palin. When narratives in the public sphere, like Palin's, favor language like "beautiful children" in need of "special love" it encourages the portrayal of people

with cognitively disability as perpetual children (Cooley, 2011: 304).This is tied to the limitation of expression in the current neoliberal table our culture is set on; where those with cognitive disability are only welcome to contribute when the contributions made are "deemed appropriately creative, robust, and decent" (Cooley, 2011: 312).

The publicity of these narratives also forces mothers to absolutely assume responsibility for the care of the child. There also exists, through out these representations, a sort of onerous responsibility on mothers and a sense that "a woman's horizon of possibilities is dimmed by the fact of her [child's] disability and unassailable notions about the mothers responsibility for [their] care" (Cooley, 2011: 307).

The increase of live births and longevity of people with Down syndrome demands that as a society we deeply and critically examine the texts, which represent this growing population and how they impact the way their identities form. If we do not continually preform careful examinations of the relationship between representation, identity, and power we are sure to miss injustices and come short in attempts to gap disparities in healthcare. The field of disability studies is a relatively new field that offers key insight into some of the issues I will be discussing, however there is still a need to more deeply develop these ideas.

Theoretical Framework

The somatic self, biopolitics, and the Foucaultian approach to power in neoliberal society are all important theoretical concepts for the reading approach I used in this analysis.

The development of the somatic self is a modern mutation of identity and personhood where the body and the self are intrinsically interwoven. The "whole-scale geneticization of identity with the consequent reduction of the human subject to a mere expression of their" genetics (Novas and Rose, 2000:489). The understanding the self through the body, genetics, and medical science are key sites of identity development with their "resolutely somatic understanding of the mechanisms of disease" and disability (Novas and Rose, 2000:490). The development of the modern self should be:

> "free yet responsible, enterprising, prudent, encouraging the conduct of life in a calculative manner by acts of choice with an eye to the future and to increasing self well-being and that of the family" (Novas and Rose, 2000:490).

The way individuals understand themselves and other are being shaped by these ideas. "Practices of subjectification that operate in genetic terms", like medical imaging, blood and other medical tests, illness narrative, and many other methods are incorporated in a multitude of "ways of thinking about and acting upon human individuality in 'bodily' terms" (Novas and Rose, 2000:491). These developed biomedical identities "infuse, interact, combine, and contest with other identity claims" (Novas and Rose, 2000:491).

The traditional concept of power is as something to be wielded and acted upon others. However, Foucault has a different conceptualization of power that is important in

my analysis. Power to Foucault is a relational network that is altered and shifted by the actions of individuals. The age we live in is a 'biopolitical' age and our "politics call his existence as a living being into question" (Foucault, 1979: 188). A panoptic order or panopticon is a system in which authority is in a central figure that sees all without being seen. The persons on the outer ring are brightly lit and are precisely the opposite of the authority; they are always seen, but never see. The quarantine of diseased bodies separated each individual into his own place, body, disease, well-being, and even death. The appeal to the body and its biological nature "individualizes human worth", and "discriminates against, constrains or excludes those found to be biologically abnormal or defective" (Rose, 2001:2) supports the process by which bodies of difference are targets of normalization and optimization.

This separation is also important because Foucault suggests that these separated individuals with maintain order, discipline, and monitor themselves and each other. This means that harsh central acts of discipline and punishment are obsolete. This machine of power is independent of who is the operator and can sustain. Unlike regimes of governments, Foucault implies this method of power relations is an unchanging presence that morphs to democratically changing norms of discipline and punishment. The power relations in the neoliberal political order has "mistaken social norms for vital ones" where features of the somatic self like emotion or impairments are seen "as errors open to correction in the name of social, not a vital, norm of health" (Rose, 2001:19). The continuous self-monitoring and punishment, stigmatization, and dehumanization of individuals who are different or act out of the desired order exists in a sphere beyond the government, companies, or any other institution.

This power relation exists dynamically through all of society in an interdisciplinary fashion. Most decisions, especially medical and reproductive ones, and their rewards or consequences are placed solely on the individual even though family units and communities still exist. The network of power in these decisions maintain a pastoral or relational tone where genetic counselors and medical professionals gate keep and guide "actual or potential parents who are making their reproductive decisions" (Rose, 2001). The structure of the modern society is rendered so "the management and maximization of life itself [...] the life's work, not only each individual, but of their doctors, together with the scientists, entrepreneurs and corporations who make the reworking of life the object of their knowledge, inventions, and products" (Rose, 2001:17).

Analysis

In today's public discourse on Down syndrome we see a variety of narratives. While there are a few narratives published by people with Down syndrome, the majority of narratives are published by parents, care takers, or other family members. In this critical analysis of selected texts I will demonstrate that several factors influence parents of children with Down syndrome and influence the realization of a varying degree of progression from disappointment, rejection, and grief to acceptance, joy, and advocacy. This will demonstrate that the representations of people with Down syndrome and their families embracing disability are viewed as extraordinary people doing what is impossible for those who are not extremely strong willed. This prevents society from actualizing the goal of embracing and inclusion for all people with disability.

It is important to start with some understanding of how the selected texts portray society's perception of people with Down syndrome. The way the authors of these narratives and society perceive people with Down syndrome plays an important role in all the narratives and how parents are able to progress beyond grief, despair, and rejection. Sophie Horan shared her story of experiencing a Down syndrome pregnancy on Yahoo! Parenting. The article titled "Why I Terminated My Pregnancy After Learning My Baby Had Down Syndrome" has many aspects that are especially important in this analysis. A portion of Sophie Horan's article demonstrates a dangerous dichotomy between people with Down syndrome and people without Down syndrome. Horan's fear of becoming the family in the café exemplifies the perceived need for the optimization of the body as productive agent. The fears of Sophie as she described the young man in the café behaving "like a rambunctious toddler [and wondering] if he were a teenage or older" (Horan, 2015) are founded in the enforcement of the idea that a person ought to mature and develop to contribute to society. Here the reader is already poised to see people with Down syndrome as fundamentally different from themselves. This is a way in which contemporary society divides individuals and focuses attention on the self as experienced through the body opposed to the interconnectedness of individuals who having meaning outside of their bodily experience.

While negative representations separate people with Down syndrome, even positive representations can be distinctly limited. Some narratives supply an oversimplified picture of children with Down syndrome as continuously joyful and amiable. The saccharine nature of these representations hides the natural range of expression that is still present in children with Down syndrome. "Welcome to Holland" is

a short narrative from mother, Emily Perl Kingsley first published in1987 that is still circulating today. The representation of a child with disability in this text is unipolar and therefore limiting. This text presents all children with disability as "slower-paced" and "less flashy" than the typical child parents expected. This builds a regime of truth in which children with disability are incapable of varied existences. The distinction between the trip to Italy or Holland made by Kingsley builds a belief that children with disability are intrinsically different, slower-paced and less flashy than children without disability. This limited perspective has begun to be pushed against, and people like Lindeman, the mother who wrote an online article for the *Washington Post* in the summer of 2015 that directly challenged the idea that routinization of pre-natal testing, are publicizing narratives showing their children with Down syndrome are "fascinating, demanding, delightful, present, annoying, dependent, loving, cuddly, different, unpredictable and completely human" (Horan, 2015).

People with Down syndrome who normalize and optimize their lives and behaviors to minimize the somatic impairments caused by having Down syndrome are the positive portrayals seen in many texts today The memoir *Choosing Naia* was written by *The Boston Globe* reporter Mitchell Zuckoff. This book received honors from the national Down Syndrome Congress, the American Association on Mental Retardation, and many regional groups in support of people with developmental disabilities. It is a telling of the journey of Greg and Tierney Fairchild from pregnancy to the first years of life of their daughter with Down syndrome, Naia. Ashley Wolfe was "the poised young woman who appeared in the Connecticut Down syndrome Congress videotape" that Greg and Tierney watched while making their decision between terminating or continuing the

pregnancy (Zuckoff, 2002:267). When they met later Greg and Tierney were "struck by her intelligence and poise" (Zuckoff, 2002:267). She was twenty-three years old with a job at Harvard and "a budding career as an actress and motivational speaker" (Zuckoff, 2002:267). The manner in which Ashley lives is tailored to the productive norm, and encourages a subversion of her and others disability in lieu of embracing the difference and possibility for worthiness and quality measured in a way other than how normal a person with Down syndrome can be. The way she is described physically as "petite [...] with dark blond hair, blue eyes behind gold-rimmed glasses, and a soft, breathy voice" (Zuckoff, 2002:267) also subdues Ashley into social norms of a normative body and the productivity of the self through that body.

The ability of parents to make any progress towards embracing a child with Down syndrome begins with this perception of people with Down syndrome and prenatal screening. Throughout these texts we see the important role of prenatal testing in the public discourse on Down syndrome. Some narratives support the process and demonstrate the influence of normalization and optimization on public discourse, while others challenge the routinization and intention behind the tests. Screening for Down syndrome has distinctly shaped the public discourse on children with Down syndrome and their parents. Renate Lindeman wrote an online article for the *Washington Post* in the summer of 2015 that directly challenged the idea that routinization of pre-natal testing is a good thing. Her title, "Down syndrome screening isn't about public health. It's about eliminating a group of people" directly challenges the idea of self-monitoring and responsibility of the mother to classify and characterize her expectant child into a normative framework. The subtitle, "Life with Down syndrome is still worth living"

makes a strong statement against the idea that all individuals are worthy only when their lives are optimized and normalized to be productive members of the normative society. Her subtitle orients readers in a way that signals she has made a clear transition to a belief that Down syndrome does not devalue life in any way.

Lindeman opens with the familiar shattering of her worldview when her first child was born with Down syndrome. She said that when she gave birth to her "first child 11 years ago, I Heard the words 'Down syndrome,' and my world collapsed" (Lindeman, 2015). She was haunted by "visions of children sitting passively in a corner watching life go by, not participating" (Lindeman, 2015). This crushing negativity is the normative response to a child of difference. The representations in today's public discourse shape this belief that mothers and fathers should be devastated when an expected child has any form of impairment or disability. Her fear of a passive life for her child shows our deep-rootedness in the ideal of optimization and productivity of the body. This is to say our somatic experience is only valuable when it lends to a desirable purpose identified by collective discourse. The fear instilled in Lindeman, as mother, is a normative response to a child of difference because it is the way one should react to having an abnormal child. Public discourse on a pregnancy of a child with Down syndrome or some other difference says mothers should mourn the loss of the expected child. There is no place for celebration in a pregnancy of difference. In all of these narratives we do not see any celebration, joy, or admiration like we are expected to act when experiencing a normal pregnancy.

Another narrative aligns with the framework of Lindeman's progression in relation to prenatal screening. Sophie Horan shared her story of experiencing a Down

syndrome pregnancy on Yahoo! Parenting. The text begins with a picture of a white woman's pregnant abdomen and a hand firmly placing an ultrasound wand on her. Below the photograph is the text, and it poignantly beings with "'You're lucky', the nurse said during my first trimester prenatal exam. 'With this new blood test, we'll be able to check for chromosomal abnormalities without you having to take a CVS or amnio". Paired with the solemn title "Why I Terminated My Pregnancy After Learning My Baby Had Down Syndrome" this upbeat opening line points out the hard division between 'normal' pregnancies and Down syndrome pregnancies. The nurse assumes that Sophie will be getting a screening test as a responsible mother. Sophie leads her narrative with a qualifying paragraph explaining the difficulty she and her husband experienced conceiving a child. At the age of 42 Sophie conceived, but unlike many mothers over 35 she and her husband "were so blissfully happy that [they] hadn't yet discussed having a CVS or amnio" (Horan, 2015). Even though eight weeks into the pregnancy she had not yet talked about CVS or amniocentesis, but opted to receive them even after hearing how uncomfortable and down right painful the testing. Sophie made sense of her decision to receive testing opposed to listening to mothers who refused by stating "I needed to know whether my baby was healthy and normal" (Horan, 2015). Here Horan supports the argument that normalization and optimization are main goals of prenatal screening, and readers are supposed to feel familiar with her need to know if her child was not only health but "normal" too.

Not unlike Lindeman's narrative, in the memoir Greg Fairchild, father of Naia, provided further support for the argument that knowledge gained from prenatal testing is not holistically good and for the betterment of the mother and child's lives. He supports

the social model of disability by stating, “people don’t want to give up the shield they have from discrimination. […] And people know that a child with Down syndrome will feel discrimination” (Zuckoff, 2002:55). Then Greg reveals the concept of rejecting the family’s “overstating [of] their supposedly objective medical knowledge of the heart defect and its interaction with Down syndrome” (Zuckoff, 2002:55). He states that some people “don’t want to deal with [discrimination], people will tend to seek out information that confirms their belief that [continuing the pregnancy] is something you shouldn’t do” (Zuckoff, 2002:55). He continues with the prediction that “when this is all said and done, if it turns out more positively than everyone expects, some people will see us as having been pioneers” (Zuckoff, 2002:55). The other side comes from Tara, his sister-in-law, that “if it doesn’t turn out as positively as you expected some of them will see you as having been stupid” (Zuckoff, 2002:55). Here we are stuck in the middle of these two views. In one way the reader is expected to feel a sense of rejection of the medical model of disability. Nowhere in the other selected texts is there such a strong assertion of the possibility of “overstating” “supposedly objective medical knowledge”, and this creates a sense of unease in the simple acceptance of prenatal testing as a method of knowledge acquisition that is universally good. However, the idea that a positive outcome would shine a light on the family as pioneers is troublesome because it suggests that Greg’s challenge of the weight and objectivity of medical knowledge is something extraordinary or even risky.

However, the insertion of this argument in the narrative plays an important role in realigning the worth of prenatal screening. When Tierney, mother of Naia, attempts to “cool them both” she appeals that they “haven’t even talked with the specialist yet”

(Zuckoff, 2002:55), as if this person were a pure source of infallible knowledge on the matter. She pleads that they are "not at the point of having this conversation yet. We should wait and see" (Zuckoff, 2002:55). This end to the conversation places readers square in the middle of the two opposing sides, and in a state of confusion and indecision. This part in the narrative develops an unresolved tension between the idea that prenatal testing provides holistic objective knowledge about the medical disability and the social model of disability in which people's attitudes create the obstacles faced and not the impairment of their body. Tierney's comments pull use back to seeing the continued reliance of doctors, prenatal screening, and other medical information for moral decisions.

The end of Horan's narrative is a culmination of reliance on medical information and the perception of people with Down syndrome. After seeing the young man at the café and receiving all the test results Horan questioned her social worker "Could you please tell me if the baby is a boy or girl?" (Horan, 2015). Subsequently she bursts into tears and states that "only then, after I'd gotten to know my baby as well as I possibly could" was she prepared to "make the hardest decision of [her] life" (Horan, 2015). Here Horan epitomizes the neoliberal idea that people are defined by their somatic self, and medicine especially genetics allows us to know everything about others and ourselves.

The determinants of progression in each narrative are not limited to perception of Down syndrome and prenatal screening. The social and economic context of each author also supports or stifles the realization of transition. The social and personal presence of a religion is another important source of difference in progression towards a positive embracing of a child with difference. It is after the emergency caesarean section that

brings his daughter, Naia, into the world that Greg reflects on the word Grace. Tierney and Greg chose Grace as the middle name for their baby girl, but it was not for any traits of gentleness, beauty, or femininity of their child. Instead Greg saw grace as forgiveness, and though the birth of a child with Down syndrome "has not been easy on our family, I believe, or I wish, that the baby will do more to raise people, to change people's expectations and beliefs. She provides an opportunity for people to have grace. To mend bonds that were strained" (Zuckoff, 2002:139). This acceptance, even celebration, of difference in this child refutes the assumption Down syndrome is only a challenge to be overcome, normalized, optimized, or eliminated. The Christian context of the Fairchild family is of great importance here. In his reflection on the word grace, Greg heavily imparts values of his Christian upbringing and worldview. The tie between forgiveness and the word grace relate back to the biblical concept of Gods grace, or mercy on believers. Though it is clear that there are no explicit ties to religion, Gods grace or appeals directly to God the predominately Christian context of the selected texts support the argument that religious involvement or environment impacts the progression to acceptance.

The social and economic contexts also interact in these narratives in ways that are not discussed in any of the texts. The social context of a capitalist democratic nation with no national healthcare system pairs with economic standing to highly limit the power of the selected narratives. None of the narratives discuss any of the economic complexities of health care, pregnancy, and parenting a child with Down syndrome. All of the authors are relatively well off, and all presumably have insurance. This is an extremely limiting aspect of the narratives that fails to connect to poor and uninsured mothers. These texts

demonstrate a failure to recognize the voice of a large group of people who have a legitimate stake in the public discourse on Down syndrome.

Without recognition of the additional challenges faced by economically disadvantages mothers we cannot hope to further the transition to inclusion and acceptance of people with disabilities in discourse or in society. Publicizing stories of pregnant mothers reliably and easily attending doctor's appointments and getting tests or procedures with no obstacles has created a regime of truth that systemically suppresses the voices of poor mothers. The belief that all mothers who do not reliably attend and listen to their doctors are irresponsible entraps poor mothers, mothers without insurance, or mothers who choose to forgo medical appointments and testing for religious or personal reasons in negative subject position.

Race is a distinctly important difference that influences the transition to acceptance in the narratives and social discourse on Down syndrome. Race is a meaningful difference that impacts individuals and society in very important ways. While disability and race are not in any way comparable, I argue that the experience of racial difference contributes to a change in the way individuals experience the difference of disability specifically Down syndrome. This text also challenged the age and racial assumptions often made about parents of children with Down syndrome. As seen in advocacy videos, like Dear Future Mom featuring a letter from a concerned prospective mother and a compilation of video responses from children and teens with Down syndrome, from CoorDown the public discourse on Down syndrome is almost completely white. Choosing Naia challenges these portrayals with the representation of the Fairchild's, a racial diverse family. Tierney's whiteness and higher education are typical

of the representations of parents of children with Down syndrome, but the fact that she was a young woman who was "five-foot-six, slim, and pretty" distinctly differs from the image of the older mother most often paired with the idea of a Down syndrome pregnancy. Greg Fairchild, Naia's father, was a young black man who "was an army brat" of a well-respected officer. Growing up relatively sheltered from the pain of racial discrimination the diagnosis of difference in their expectant child "unleashed a torrent of thoughts on being black […], and on discrimination based on race and disability" (Zuckoff, 2002:27). The judgment of mothers of color was clear to Greg early on when the wives of foreign-born officers complained to his mother that they "felt they were treated like second-class citizens by some of the white, American-born officers' wives" (Zuckoff, 2002:73). These women knew that Greg's mother, Mary Fairchild, would understand because even though she "was one of the American-born officers wives, she was also a black woman from the south" (Zuckoff, 2002:73). This is important distinction in the narrative confirms the representation of women of color as different. This shows people of color are subjects that must view themselves a part from or normalize their ethnic background in some way order to fit into the ideal or accepted-ness of our society. This experience of difference possibly influenced the direction and speed at which Greg and Tierney moved in a progression to the positive view of Down syndrome and disability.

The way we monitor and label race as bodies of difference is especially important in the context of Down syndrome. The characterization of individuals based on race as means of labeling their worth and potential to contribute to the neoliberal order was so important that Zuckoff breaks from the narrative story line to describe it further. Zuckoff

harkens back to the 1860's when John L. Down published his paper "Observations on an Ethnic Classification of Idiots". Down suggested that some "mentally retarded white Anglo-Saxon Protestant children ended up in what he considered their pitiable state of idiocy" when their development was prevented in utero which left then "on the level of one of the so-called lower races" (Zuckoff, 2002:32). Each place in time where development had stopped had corresponding traits and inferior race assigned to it. One boy Down knew was used to describe "the first clinical description of physical characteristics common to people with […] Down syndrome" (Zuckoff, 2002:33). Down called this the "Mongolian type of idiocy", and while this "theory imploded over time" it left a mark of racial characterization that "despite their racist, fallacious underpinnings" has yet to be totally erased from the discourse on Down syndrome. In this way people with Down syndrome are put in the same subject-place as ethnic minorities in a way they can make sense of their place in the public discourse. This radicalized history situates the reader in a way that allows them to only see people with Down syndrome as white. The only people of color in the selected texts are Greg Fairchild and his parents and siblings. Though Down syndrome is more common in whites than non-whites the current representation would suggest an unrealistic distribution.

The pervasive presence of narratives of overcoming disability confirms the idea that a child with Down syndrome presents parents with an immense challenge to be overcome. Choosing Naia partially falls into this theme in several places. The narratives of Tierney and Greg as well as other couples they speak too are structured in a way that presents the prenatal diagnosis of Down syndrome and birth of a child with Down syndrome as a world crushing revelation that demands a series of strong willed actions to

overcome and raise a child or choose to terminate the pregnancy. The prologue of the novel begins by discussing a birth of a child with a deformed face in 1935, and that "back then, less-than-perfect births were always a surprise" (Zuckoff, 2002:ix). The transition from having no knowledge of a disability or difference a child may have to having the ability, or responsibility as contemporary society would view it, to find out the potential presence and severity of disability created a deep rooted tension between acceptance of disability as a variable characteristic of humanity and the normalization and optimization of the somatic self.

However, it also distinctly challenges the notion that Down syndrome is the greatest challenge faced by Naia's parents. The narrative contrasts the original perceived challenge of Down syndrome, and the expressed challenges like "other big changes in their lives" including new jobs and home. Perhaps the most poignant expression of this view came from Greg's quiet father, Bob, when he asserted, "this is not a tragedy. This is not the end of the world. All of us are born with defects" (Zuckoff, 2002:87). Here the narrative embraces difference, and realigns the emotional connection to a positive space typical of families expecting a child. The statement that we all have defects acts as rejection of the normalization and optimization of the somatic self as seen in today's society. Normalization and optimization of those with disability seeks to hide their impairments. The aim is to remove or alter difference in a way that is productive and aligns with the accepted norm or majority experience. The concept of the somatic self implies that the site of paramount importance in life is the body. The simple acceptance Bob, Naia's grandfather, asserts in the part of the narrative allows the reader to move with Greg and Tierney through the phases of the progression of acceptance.

An important caveat in this claim is the severe lack of narratives from mothers who have chosen to terminate their pregnancies. Sophie Horan's narrative challenges this absence. Sophie detailed the scene of an older couple struggling to hand feed their adult son with Down syndrome a piece of pizza as Sophie and her husband watched at this sidewalk café. After hearing the sex of their future child Sophie could not keep composure. She said it was then that she could decide to terminate her pregnancy, and she described the choice as one that was "best for her child". The resounding absence of narratives of mothers who choose to terminate prevents any deep analysis of motives in their decisions.

Conclusion

The analysis of these texts demonstrates the harmful sensationalization of parents making a transition to acceptance and joy for a child with Down syndrome. This exaggeration of achievement around a successful embracing of a child of difference encourages the perception of a child with Down syndrome as unmanageable challenge for most families. A separation between author and reader is made that suggests the author of these narratives possesses something special, which the reader does not possess, that allowed them to overcome. There is a definite need for more critical inquiry in order to begin to create a more holistic understanding of how representation of parents and people with Down syndrome impact the power relations and public discourse on Down syndrome.

There are several limitations of my analysis that could be improved by further critical inquiry of this issue. The first limitation I encountered is the small number of texts I selected for analysis. Due to the time constraints of a semester and a half in

undergraduate university I was unable to select a larger number of texts to provide additional support to my critical claims. I was also limited by the scope of my texts, which only occupy one nation in a relatively small time period. Further studies could investigate the temporal and national variables impact the understanding of Down syndrome. Finally my analysis was limited by its concentration on one type of disability. Future inquiry should be made to analyze how disabilities other than Down syndrome are represented and what impact these narratives have on the actualization of inclusion and acceptance of people with disability in the modern world.

Despite the limitations of the current paper, several important claims were made to support the assertion that factors like prenatal screening, social and economic context, and a pervasive presence of narratives of overcoming limit the progression of the public discourse to acceptance and inclusion of people with Down syndrome. The critical analysis here provides a partial perspective that may aide in promoting further inquiry into how society can attempt to actualize the goal of embracement and inclusion for all people with disability. In conclusion, I believe that this analysis demonstrates that the representations of people with Down syndrome and their families embracing disability are extraordinary people doing who uniquely posses experiences or something undefined.

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