

A Quality of Life Perspective on the New Eugenics

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Abstract

Quality-of-life is a concept that has had robust development and application in the field of intellectual disability in recent decades. It functions as an apt goal for individuals to enhance their lives, as well as for policy and disability support. Quality of life helps address ethical issues by acting as a key guidepost in ethical considerations. Current philosophical and human rights approaches to disability support the view that intellectual disability is no reason to assume poor quality of life. Moreover, individuals with intellectual disabilities themselves typically rate their own quality of life quite high. Similarly, families perceive disability as contributing to family quality of life in some ways, although this is tempered by social constructs, especially normalcy, that support marginalization and discrimination. Disability Studies, and critical disability theory that constitutes much of its foundation, offer an alternative perspective of intellectual disability that values its contribution to larger society—intellectual disability as a positive and necessary aspect of the diversity within the human mosaic. It is argued that this perspective of intellectual disability negates the necessity of new eugenics practices.

Quality of life is a term that has come into wide use in recent decades, both in the popular and the academic realms. Its focus on positive aspects of life positions it well as an appropriate concept for constructing goals to which people might aspire and to assess the degree to which improvements might be made to enhance people's lives. Based on this general understanding, the concept quality of life has made its way into innumerable mission statements of organizations and stated purposes of societal institutions in recent decades. Indicators of quality of life have also been tracked and recorded in many venues and for increasing numbers of purposes, but particularly to evaluate supports and services of various kinds and to assess how they might be improved.

Quality of life and family quality of life—as both concepts that include principles and value statements, and as areas for research and application—have developed robustly within the field of intellectual disabilities. An international consensus on quality of life conceptualization, measurement, and application was first published by Schalock et al. in 2002, and has since expanded (Brown, Cobigo, & Taylor, 2015).

Quality of life in intellectual disabilities deals with both how life is judged by others, and how life is experienced by individuals and families themselves. Others judge life conditions as assessed by sets of objective indicators relevant to specific cultural contexts (health, education, income, housing, etc.), or by people's satisfaction with indicators within pre-determined life domains (Brown, Hatton, & Emerson, 2013). For individuals and families, though, quality of life emerges from their own perceptions of how good life is for them. It is the personal and sometimes unique set of thoughts and feelings that reflect their particular views of the world around them and their lives within that world. It includes exercising personal choice, developing self-image that well may include disability, and is increasingly relevant across the lifespan as people with intellectual disabilities form a larger part of their societies and as they live much longer than was the case in the past. In the field of intellectual disabilities, an objective approach to assessment can be of interest in constructing social policy and organizational objectives (Schalock & Verdugo, 2012), such as improving accessibility and social inclusion in a general way, but the

latter approach is essential for addressing quality of life of individuals and families because it is based on perceptions through their eyes of their own bodies, their own set of abilities, their own environments, and their own cultures (Schippers, Zuna, & Brown, 2015).

Assessment and application of quality of life invariably border on matters of ethics. Inasmuch as ethics addresses the best course to follow in a particular situation, quality of life acts as an important guidepost for making ethical decisions. Its main contribution is to focus attention on what, in a particular situation, acts to enhance quality of life, especially from the point of view of the person or family in question.

In this paper, we take a quality of life perspective, using quality of life as the key guidepost, to examine ethical aspects of the new eugenics. Building on the original intent of the eugenics movement—to improve the genetic makeup of society by taking action to influence procreation—we take the “new” eugenics to concern itself primarily with more recent methods of minimizing the presence of severe disability within our broader societies. We will argue, both from a philosophical perspective and a human rights perspective, that the presence of disability is no reason to assume that life is of inferior quality. We will further argue that people with intellectual disabilities generally rate their own quality of life quite high, and that “others” valuing and understanding the lived experience of disability within the family and within society negates the necessity of most eugenics practices.

CURRENT PHILOSOPHY AND THE NEW EUGENICS

Support for new eugenics practices appears to be based on the idea that a life with disability, especially one with severe disability, is troublesome and lacking in quality for the individual with disability and supporting family members. Because of this, it is assumed, there are many cases where it might be ethically prudent to terminate a pregnancy where a disability is detected or not to continue medical treatment where disability seems inevitable and recovery improbable.

Current philosophy that acts as the backbone of Disability Studies worldwide, termed critical disability theory, contradicts this point of view (see Cameron, 2016; Goodley, 2013; Reaume, 2014). Critical disability theory, like its identity and emancipatory theory cousins (especially feminism, race theory, and gender identity theory), recognizes that disability is part of the human spectrum in all societies and that action needs to occur to reconceptualize disability as an equal and valued part of this spectrum. Disability is the result of established concepts, language, and institutional structures that give “ableist” power to nondisabled people, and both marginalize and discriminate against people with disabilities (Procknow, Rocco, & Munn, 2017). Critical disability theory further holds that overt action needs to be taken to redress this wrongful conceptual and power imbalance (Goodley et al., 2018). Reaum (2014) wrote, “In the emergent field of critical disability studies...[people’s] experiences...are understood in the context of the barriers society placed on the[m]... —barriers that served to pathologize, confine and ostracize them. Above all else, this new discipline allows disability...to be understood from the perspective of the person who experiences it, as much as this is possible.” From the critical disability theory perspective, then, individual disability is not seen as something that is troublesome or lacking in quality, but rather as something that results from a lack of understanding of the individual’s lived experience and from the strong social and material barriers that have been put in place to devalue disability and to marginalize people with disabilities. New eugenics practices, unfortunately, perpetuate the status quo by using numerous and sometimes insidious methods to devalue the human experience of disability. They act against full social acceptance and inclusion, and in this sense they are at odds with the current philosophy of the worldwide disability community.

Critical disability theory goes beyond confronting what has been wrong with past conceptualizations of disability and our responses to it, by suggesting a more positive way forward. In fact, its main objectives, as explained by Brown, Wehmeyer, and Shogren (2017, building on Pothier &

Devlin, 2006) are “empowerment, equality... and emancipation” (p. 7). To achieve these objectives, we need to confront the true intent of our current conceptualization of disability and our power structures. For example, treating disability as something that requires support and accommodation only functions to continue to pathologize it (Goodley et al., 2018), while changing the lens to providing environments that enhance quality of life for every citizen and to value the experience and contribution of every citizen functions to expand empowerment, equality, and emancipation. These objectives go beyond merely accepting and tolerating disability, and rather see disability as a positive contributor to human diversity that merits celebration (Campbell, 2008). Although this thrust does not specifically address new eugenics practices, it does strongly suggest that the contribution of disability as one aspect of human diversity is valuable to the entirety of the human experience. As such, it contradicts the view that disability is a condition that inherently lacks quality and value.

HUMAN RIGHTS AND THE NEW EUGENICS

It is something of an irony in a discussion of the “new” eugenics to note that the “old” eugenics, which was widely adhered to in the Western world both as an ideology and a comprehensive set of practices, came to a crashing halt more than half a century ago. The central concept of the “old” eugenics was that some people within a society were inferior and a detriment to its progress, and therefore were numbered among those who were not wanted in the future. One rationale for this was that, for a person diagnosed as “mentally defective,” intellectual development was very limited, giving rise to the phrase “once a defective, always a defective.” As history has recorded, this view began to challenge moral limits beginning in the early 1920s (e.g., sterilization of the “feeble-minded” and other “degenerate persons” in some countries, a movement that emerged from social Darwinism; Cohen, 2016). This view was extended through World War II, especially in some European countries and in North America, when whole groups of people began to be identified as not belonging within society, and others were deemed to be a scourge to society. In Nazi Germany, especially, large numbers of people--millions of Jews, tens of thousands of people with mental illness, thousands of children with disabilities, and others--were grouped together and deemed to be not worthy of living (Aly, 1994; Brown, 2018; Friedlander, 1995). When the horrific undertakings of the Nazi concentration camps were finally discerned following the cover of the war, eugenics as a viable ideology suffered a near-death blow. A focus on human rights quickly emerged in its place, as evidenced by the proclamation of the United Nations’ *Universal Declaration of Human Rights* on December 10, 1948.

Human rights placed a renewed emphasis on the equality of all humans. The word “renewed” is used here purposely, because Western culture has a very long history of recognizing some rights of people whom we would now describe as having disabilities from antiquity (Berkson, 2004, Stainton, 2018) through medieval times and the industrial revolution (Bach, 2017; Berkson, 2006; McDonagh, Goodey, & Stainton, 2018). In particular, legal status and personal dignity were supported over several centuries by philosophies such as charity and humanitarianism, in spite of strong pressures to the contrary from social class structures, economic and rural-urban changes brought on by the industrial and technological revolutions, and by human merit increasingly being “scientifically” judged by the standards of rational thought and contribution to progress. Human rights, then, has had a long and sustained presence in Western cultures, and in recent decades it has become more global, exemplified best perhaps by the proclamation of the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). An important value that emerges from the Convention as a whole is the importance of disability as a viable and worthy part of a diverse human mosaic. This progression on rights argues strongly, even if somewhat indirectly, for the equal treatment of all people, including all people with all disabilities (Pinto, Rioux, & Lindquist, 2017). Consequently, it argues against the unequal treatment of fetuses, infants, children, and adults with disabilities that is evident in the new eugenics.

HAPPINESS, QUALITY OF LIFE, AND THE NEW EUGENICS

The quality of life of people with intellectual disabilities began to be studied in some depth beginning in the early 1990s. Personal responses to multi-item quality of life questionnaires obtained by several researchers (e.g., Brown, Brown, & Bayer, 1994; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; see Cummins, 2010, for a review of commonly-used scales) strongly indicate that people with mild and moderate intellectual disabilities can reliably assess their own life satisfaction, and many attempts to assess quality of life of people with severe and profound disabilities have been undertaken (e.g., Petry & Maes, 2008).

In general, people with intellectual disabilities rate their own happiness quite high. When assessing their own happiness, 93% of a large Finnish sample responded that they were happy (Matikka & Ojanen, 2004). Cummins, Lau, Davey, and McGillivray (2010) also noted that adults with intellectual disabilities rate their personal well-being at high levels, and that these are comparable to the ratings of non-disabled people. A large Canadian study found that adults with mild and moderate intellectual disabilities rated their quality of life similarly highly, and significantly higher than did their closest caregivers (family members or staff; Brown, Raphael, & Renwick, 1997; Raphael, Brown, Renwick, & Rootman, 1996). These examples from the available literature point to the fact that people with intellectual disabilities view their own lives as quite positive, and that it may be “others” who primarily see their lives as having lesser quality. Albrecht & Devliegher (1998) referred to this as the “disability paradox” based on their study on people with disabilities perceiving a high quality of life “against all odds” (p. 977). If the new eugenics is basing its practices on the assumption that people with intellectual disabilities lead lives of low quality, it is not reflecting the views of people with disabilities themselves.

One explanation for relatively high quality of life ratings, no matter what disability people may have, comes from Cummins’ work on homeostatic effects on subjective well-being (Cummins, 2017, 2018; Cummins, Lau, & Davern, 2011). Based on extensive research that uses databases spanning more than three decades, Cummins has determined that almost all people have set-points of happiness—typically between 7 and 9 on a 0-10 scale—that are genetically determined and protected by homeostatic control. By this, he means that people have a “usual” point on the scale that represents their emotional state, and that we all have built-in homeostatic control that returns us to this set-point when we are elated (very happy or excited) as well as when we are depressed, saddened, frustrated, or angry. The principle of homeostatic effect leads to the strong possibility that people with intellectual disabilities, like all others, have a genetically-driven tendency to see their lives in fairly positive terms, and when conditions arise that move them up or down from their set-point, they have a natural (non-cognitive) ability to return to their usual mood state. This line of thinking also argues quite strongly against “others” pre-determining that disability leads to lower life satisfaction or quality of life.

“Others” have made other unwarranted assumptions about the happiness and quality of life of people with intellectual disabilities, and these assumptions have contributed to the new eugenics. One assumption is that people with intellectual disabilities have a lower quality of life because they do not have what nondisabled people have. But as disability advocate Tom Shakespeare (n.d.) has pointed out, people with disabilities live the only life they have ever known, and are not unhappy that other people have abilities they do not. They are used to their bodies as they are, and their identities and self-images have emerged from their own bodies and their own functioning (McLaughlin & Coleman-Fountain, 2014). Their lives are not marked by “unbearable suffering” as the new eugenics sometimes leads us to believe, but are simply the way they experience themselves and the world around them. Another assumption is that people with intellectual disabilities have reduced feelings. But research of Kyrkou (2018), for example, has pointed out that we have grossly misunderstood what we thought must be a limitation on being able to recognize and experience pain. A final example involves the assumption that

nothing medically can be done to help. In fact, the entire new eugenics approach seems to limit societal institutions and some professionals from believing it is worth providing high levels of medical support. As has been pointed out elsewhere in this volume, however, medical science is advancing at a very fast rate. Blindness was considered to be permanent throughout most of history, but recent advances now strongly indicate that stem cell therapy, gene therapy, electronic device implants, and other interventions are showing results and will bring at least some sight to many blind people within the next few decades. It is important to examine these and other assumptions we have about intellectual disability very closely, because we may have been wrong up to this point. There may be another way of looking at the situation, one that does not indicate compromised quality of life. In any case, medical advances in the future may prove much of our thinking to be faulty or, at the very least, to be outdated.

FAMILY QUALITY OF LIFE AND THE NEW EUGENICS

Since 2000, there has been considerable research conducted worldwide on family quality of life. This research assesses families' own perceptions of their satisfaction and attainment with regard to various aspects of family life where disability is included. Overall, the results show some areas of common strength within most families around the world (especially positive family relationships), but it also identifies areas of dissatisfaction, feelings of exclusion, and a perception that the burden of care is onerous (R. Brown & Schippers, 2016; Schippers & Van Hove, 2017). An argument in support of new eugenics practices is that they help to alleviate such negative feelings.

A plausible explanation for negative feelings in family quality of life, though, and one that argues against new eugenics practices, is the social tyranny of normalcy—the acceptance by most “other” people of the idea that there is a “normal” in society that governs how people should behave and how they should be judged. The concept of normalcy, a relatively recent social construct (Davis, 1995, 2010), has been helpful to the social sciences in some ways, but it carries the distinct disadvantage of dichotomizing people, their abilities, their behaviours, and their ways of living into “normal-abnormal.” Because normalcy is a widely accepted concept, it is not surprising that studies reported by, for example, Gray (1997) have found that parents perceive themselves as not being able to live a normal life due to disability in their families. In a recent in-depth study of family quality of life (Boelsma, Schippers, Dane, & Abma, 2018), this view was corroborated and explained. Families felt confronted by norms—presumed standards related to what is considered to be normal—in their daily lives through their interactions with others. It was through the social environment, not the internal lived experience of the families, that these norms were imposed on them (thus, the “social tyranny” of normalcy). But the strength of the concept of normalcy is at odds with the Disability Studies key assumption that society has a responsibility to provide for all of its citizens in an equitable way. It follows, then, that if the “normal-abnormal” dichotomy were reconceptualized as “equal aspects of human diversity,” negative family feelings would be mitigated and positive aspects of both the immediate and broader societal environments would support the emergence of positive family quality of life. Such a situation should negate the necessity of new eugenics practices.

Genetic counselling is a clear example of the social tyranny of normalcy that supports new eugenics practices. When expectant parents are faced with the possibility or even the certainty that their child will be born with a genetic or physical disability, genetic counselling is typically recommended. Inherent in this recommendation is the stated or unstated concept of what a “normal” fetus should be, and the notion that the parents are victims of a misfortune because their baby will not be “normal.” The principal reason for genetic counselling is to fully inform parents about what lies ahead, but it also typically presents various options to them as courses of action. One of those options, where legal, is abortion. In many parts of the world, including most developed countries, women have the legal right to choose abortion if they wish. Such freedom is widely considered to be a matter of human rights for

women, where a woman's control of her own body and freedom to make choices about her body override the right to life of a fetus. Although there is obvious value in upholding such a right, as well as the right of well-informed parents to choose, it can be part of the social tyranny of normalcy inasmuch as women who choose not to abort are then blamed for choosing "abnormal" when they had the opportunity to avoid it.

There seems to be little doubt that, in spite of the many accommodations and the adoption of rights for people with disabilities in recent decades, public policy in most countries of the world has moved rather quickly in a direction away from accepting full social responsibility for disability. Over the past 30 years, governments in most developed countries have reduced or eliminated provision of direct care for both children and adults with disabilities, and instead have increased support for families in their home settings. Although this policy is generally in keeping with the principle of normalization (Wolfensberger, 1972) and our current ideology of community inclusion, it has the disadvantage of placing the primary responsibility on parents and other close family members without providing adequate support (I. Brown, 2008, 2013; R. Brown, 2017). This might well be viewed as blaming the victim, with provision of some supports (financial and human) as primarily avoidance of guilt. New eugenics practices offer a rationale for social structures to avoid responsibility for disability, and, simply by being viable, they further reinforce their own value by devaluing disability. In this view, new eugenics practices are pernicious to families both directly and indirectly. A more supportive solution is to find new ways to share family and social responsibility for all people, including all people with disabilities. To facilitate this process, it seems essential to reconceptualize disability in such a way that it is understood as an important and valuable part of human diversity. Within such an environment, families would surely flourish as a necessary part of the larger human family, feeling that they belong.

THE NEW EUGENICS: WHAT NEEDS TO BE DONE

Some tendrils of the original Eugenics movement have remained alive, and challenge us, even today. Individuals with intellectual disabilities are still largely seen by others as deficient and as less than "normal." Because of this view, various other life restrictions are imposed, not just to those with intellectual disability but also to their family members. For example, in most developed countries, when someone wishes to immigrate and has been identified as having a disability, they are assessed by the relevant immigration department. Medical, psychological, or educational tests are required, not always appropriately. Individuals classified as disabled are then said to be a health and education risk or a burden to the social service system, and the individual with disability and the family are denied immigration unless they leave the person with disability behind. This issue is one of "Eugenics follows on," of which there are many other examples. A quality of life approach, in keeping with the main thrust of Disability Studies, would eliminate such practices by stressing equal treatment of all people and a dissolving of the ability-disability dichotomy.

What seems clear from the discussion in this paper is that policy, practice, and indeed all the societal structures that constitute the "others" to people with disabilities need to direct their attention first and foremost to the lived experience of people with disabilities in an effort to alter their values and practices concerning the place of disability in our societies. Included in these "others" are academics and researchers who often form research questions and make both recommendations and decisions on behalf of people with disabilities. The core question for "others" is what individuals with disabilities and engaged family members feel about their own lives, what questions they consider in need of being addressed, and what changes need to be made to ensure their happiness and their life quality. Hosking (2008) wrote, "It is only by listening to and valuing the perspectives of those who are living disabled lives that the able bodied can begin to understand that even severe disability does not have to prevent a joyful and desired life" (p.13).

The new eugenics appears to take a perspective of disability that is no longer espoused by the international disability community. In short, the new eugenics perspective assumes that disability is a problem that we would be better off not to have, and that people with disabilities and their families do not enjoy good quality of life. Our current philosophical and human rights perspective on disability, best articulated by Disability Studies, views disability as a viable and valuable aspect of human social diversity, and people with disabilities as equal and important members of society. It asserts that people with intellectual disabilities can and do live good quality lives, and that having an intellectual disability by no means automatically signifies a poor quality of life. It recognizes that considerable action is required to confront the entrenched structures that perpetuate marginalization and devaluation of people with disabilities, but it is hopeful of a world where the larger good accepts and welcomes the full participation of all of its citizens. Quality of life for all can be the key guidepost as we work to achieve this goal.

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