

Disability Studies Ethics: Theoretical Approaches for the Undergraduate Classroom
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Abstract: By challenging disability prejudice and advocating for people with disabilities in crucial bioethical debates, disability rights activists and scholars have been reformulating ethical discourse. This essay suggests pedagogical strategies for introducing undergraduates to an ethics of disability studies, and integrating disability perspectives into broader questions of social justice.

Key Words: ethics, disability studies, social justice

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Introduction

Disability studies scholars and rights activists, in their shared commitment to challenge stigmas around physical and cognitive impairments and advocate for full integration, self-determination, and maximum civic participation of disabled people, often find themselves engaged in reconfiguring ethical theory, debate, and action. At the heart of disability studies lies an ideal of social participation for all people, to the fullest extent possible, regardless of impairment diagnosis. This ideal positions disabled and nondisabled people as moral and legal equals, and does not formulate citizenship or personhood standards around rationality, independence, or self-sufficiency, as many ethical and social justice theories have done traditionally. In challenging physical and cognitive norms—as these have been defined and enforced—as well as historical exclusions of people with disabilities, an ethics of disability demands an expansion of long-standing conceptualizations of human embodiment and conscious engagement.

Discussing ethics from a disability perspective becomes all the more urgent and complex as we look at some of the most polarizing debates about human life, such as selective abortion, euthanasia, and the potential eugenic outcomes of prenatal testing and genetic technological advances. As many scholars in the field have pointed out, much of the medical and popular media representations of these debates have privileged cure and eradication of disability over attitudinal change and greater efforts to integrate and support the access needs of disabled people (Wendell, 1996; Parens & Asch, 2000; Glover, 2006).

At the University of Wyoming, as faculty members in the newly established undergraduate minor in disability studies¹ considered the layered ethical conversations that would inevitably arise within undergraduate courses, we decided to integrate ethical components across the core courses and popular electives of the curriculum². This essay introduces some of the pedagogical and theoretical approaches we are implementing by looking closely at some of the disability ethics content in three distinct courses. The first, Introduction to Disability Studies, is a required survey course, where students are encouraged to extrapolate the driving ethical commitments of disability studies within a social justice context. The second elective course, Women with Disabilities, focuses on feminist approaches and multiple perspectives of disabled

women. This course provides a unique location to explore care ethics and to introduce a few of the productive complications disability studies has introduced to feminist theories. The final required course, Supports and Services, provides students with opportunities to meet service professionals, disabled clients and activists, and policy experts who provide first-hand accounts of how local and national support systems operate. In addition, students are exposed to broader theories of human rights, social justice, and vulnerability, and are encouraged to use these critical lenses to analyze the ethical guidelines within their own fields or professions. The ultimate goal is to provide students in the minor with a comprehensive understanding of the principles animating disability studies, and with the tools for articulating and integrating these values into an active ethical practice in their professional lives—within and beyond academia.

Articulating an Ethics of Disability

As an interdisciplinary field of inquiry, disability studies draws upon many areas of scholarship to inform its ethical commitments. The introductory survey class reflects this diversity by encouraging students to identify and cull out from our course readings some of the foundational ethical principals informing disability studies. Drawing upon leading scholars and activists in the field, students investigate critiques of the medical and moral models, and explore the political salience of the British social model and the minority/civil rights model that has emerged in the United States. As the perspectives of disabled people are moved to the center, students come to realize how marginalized these voices are in mainstream public discourse, and how meanings of disability have been shaped by limiting cultural narratives built around individual tragedy, charity, and heroic overcoming.

From the outset, students are introduced to the ideals driving disability studies and disability rights, such as claims to full personhood and respect, maximum integration, and appreciation of dependencies and interdependencies. The importance of putting these ideals into practice are most salient as students are exposed to historical and contemporary exclusions of people with disabilities, the potentially oppressive power of medical authority, and the pervasive stereotypes that continue to cast disability as individual medical tragedy, moral punishment, or villainous attribute.

As students begin to unpack the medical model, they are often struck by the power of the concept of *normal* to stigmatize and exclude people with disabilities. Linton (1998) has explained this process in the following way: “The medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy” (p. 11). Davis (1999) has elaborated further, pointing out that the very idea of normal, codified during the eugenics period, is relatively new. With the institutionalization of the bell curve in the early twentieth century, Davis has suggested, “The concept of normality...created an imperative to be normal” (p. 504) by drawing stark lines between so-called normal and abnormal bodies. Readings from such scholars push students to reevaluate their own assumptions about normalcy, and many uncover conceptual exclusions within their own thinking that become illuminating. The perspective shift from the medical to the social model, as well, is quite noticeable in the classroom. Wendell (1996) has captured the nature of this shift in *The Rejected Body*: “One of the most crucial factors in the deconstruction of disability is the change of perspective that causes us to look in the environment for both the

source of the problem and the solutions” (p. 46). The invitation to look at specific environments allows students with and without disabilities to actively participate in locating barriers and suggesting ideas for more inclusive practices.

As we explore the nature of disability oppression and prejudice, students are also encouraged to approach the insights of disability studies as generative, and applicable to human experience more broadly. In this vein, we begin to focus on the ways that values produced by disability perspectives might enhance social theories, philosophical ideals, and cultural practices. In his classic essay on disability culture, Longmore (1995) has delineated the provocative nature of disability values:

“[P]eople with disabilities have been affirming the validity of values drawn from their own experience. Those values are markedly different from, and even opposed to, nondisabled majority values. They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community (p. 36).

In this formulation, Longmore has rightly drawn upon the experience of disabled people as an alternative “source of values and norms” (p. 36), and this provides an excellent starting point to discuss some of the major ethical traditions in philosophy, especially to investigate where the dominant assumptions critiqued above have originated, and how these theories continue to influence contemporary ideas and practices around disability.

While our foray into philosophy is admittedly superficial, students are introduced to key ethical theories and encouraged to think about concepts and exclusions that might affect people with disabilities. Initially, the class considers the differences between consequentialist (teleological) and nonconsequentialist (deontological) theories (Thiroux, 1998). Consequentialist theories such as egoism, and act and rule utilitarianism, share a focus upon consequences of actions, and determining rules or personal actions in order to bring about beneficial consequences. Nonconsequentialist theories, such as intuitionism, Kant’s duty ethics, and virtue ethics, differ in many ways but broadly share the assumption that human beings have an internal moral guide, or that they have the capability, through reason, to develop moral rules and abide by them. Such theories see ethics as a process of internal intuition or reflective learning. For the purposes of this paper, I’ll outline a few of the questions disability studies brings to the discussions of a representational theory in each category: utilitarianism and Kant’s duty ethics.

Utilitarianism

Utilitarianism takes as its guiding principle that everyone should act according to the greatest good for all concerned. In other words, moral action is determined by evaluating potential ramifications, and moral agents are obligated to choose the optimal act, or the one determined to provide the best consequences (Thiroux, 1998; Kagan, 1998). In practice, however, it is extremely difficult to predict the outcomes an action will have upon everyone involved. More important to disability studies, the ideal of the greatest good for greatest number often devolves into cost-benefit debates where majority interests are pursued at minority groups’ expense. The legacies of utilitarianism are evident in resource allocation debates in modern

industrialized societies, in which providing civic access, medical support, and other resources to people with disabilities center around cost-benefit analyses. Such models inevitably position those most in need of supports as least beneficial to the social fabric—assumptions built upon medical authority, which correlates increased impairment levels with decreased *quality of life*—a euphemism for lesser human worth. These arbitrary judgments portray people with disabilities as tragic sufferers who should be pitied, not as potential contributors to cultural life—or the bottom line. As Wendell (1996) has argued, this limiting mindset continues to make it very difficult to allocate disability resources, “because most people still think of disability as a personal or family responsibility, and...because public aid to people with disabilities has long been characterized as pure charity, rather than as a social investment in ability and productivity” (p. 51). In effect, utilitarian and medical model assumptions inhere within social thought and political structures and function invisibly as natural practices.

Kant

In contrast, Kant’s duty ethics assumes that as people act from a sense of innate, rational duty, they will come to agree upon universal moral rules that will guide their actions—which, following such reasoning, will tend toward the good of everyone concerned. In this construct, moral decisions are determined through reason, and are assumed to be logically consistent (Furrow, 2006). In critique of Kant’s enduring influence, Kittay (2002) has pointed out that his model connects human value and human dignity to pure rationality and moral duty:

“The capacity that elevates humans to the status of moral agents, [Kant] thought, is the rationality by which we judge if we can universalize maxims we choose for our own actions. Rational agency, he maintained, not our mere species membership, gives us the dignity of moral beings” (p. 262).

This privileging of rational agency, which implies an individual subjectivity based upon independence and autonomy, inevitably excludes people with a variety of intellectual or communicative impairments. As we explore more modern theories of humanitarian ethics and social justice, students are encouraged to ask how definitions of personhood, citizenship, and moral agency continue to reflect such ableist assumptions.

In order to trace the enduring nature of how the human is conceived through reason and competence, we consider the work of Rawls (1971), arguably one of the most influential modern social philosophers. Moving outside the boundaries of consequences and internal morality, Rawls (1971) focused upon developing a comprehensive theory of social justice by outlining the principles that should govern political structures. His goal was to determine what kind of social contract everyone could agree upon, taking into account the vast differences people hold about how to live. After looking at the basics of his theory of social justice, we consider some of the problems his philosophical framework presents to disabled people. In his theory, Rawls (1971) defined the negotiating or acting parties as *competent adults*, thereby constructing a boundary that could be used to expel many people with cognitive, communicative, or other impairments. I borrow Nussbaum’s (2002) critique of Rawls (1980), to extend the discussion of philosophical exclusions. The following quote from Rawls (as cited in Nussbaum, 2002) illustrates to students

the rational methods still used to justify exclusions of people with disabilities from social discourse, and by extension, society:

“So let’s add that all citizens are fully cooperating members of society over the course of a complete life. This means that everyone has sufficient intellectual powers to play a normal part in society, and no one suffers from unusual needs that are especially difficult to fulfill, for example, unusual and costly medical requirements. Of course, care for those with such requirements is a pressing practical question. But at this initial stage, the fundamental problem of social justice arises between those who are full and active and morally conscientious participants in society... Therefore, it is sensible to lay aside certain difficult complications. If we can work out a theory that covers the fundamental case, we can try to extend it to other cases later” (as cited in Nussbaum, 2002, p. 190).

As we consider this setting aside of so-called complications, we must ask how a theory of social justice can be built around the deliberate exclusion of people with dependencies. Also if such people are conceived of from the beginning as *difficult* and *complicated*, won’t their integration back into the social fabric be fraught with problems as well? As students consider these questions in conjunction with disability studies values and ethical frameworks, they begin to see how the social structures we have inherited are very much a product of these philosophical constructs.

Dependency, Care, and Expanding Notions of the Human Subject

With common interests in embodiment, processes of othering, misuses of medical authority, the relationships between care and dependency, and the power asymmetries inherent in discourse of the public versus the private, feminist theorists and disability studies scholars share a good deal of analytical terrain. In our course, *Women with Disabilities*, we explore these intersections by first examining some of the important ways feminist traditions have informed disability studies critiques, especially through expanding the social model to consider discourses of embodiment, pain, and lived experiences of impairment. Borrowing from Thomson (2004), we explore the way disability enhances and broadens the conceptual framework of feminist theory, especially theories of justice. As Thomson has suggested, “understanding how disability operates as an identity category and cultural concept will enhance how we understand what it is to be human, our relationships with one another, and the experience of embodiment” (p. 76). In order to extend the conversation of disability ethics, this course investigates these intersections within the ethics of care tradition, and then looks closely at how feminist philosophers Kittay (2002) and Nussbaum (2002) have attempted to integrate disability into their own theoretical approaches to ethics and social justice.

As a starting point, students are introduced to the relatively new but sophisticated feminist literature devoted to an ethics of care. While this tradition reflects a wide epistemological scope, it is generally concerned with grounding moral knowledge, not in universal abstractions, but in relational knowledge and insight. Held (2006), who has written extensively on the subject, suggests that most ethics of care theories share several major features. Among these, the following three are most relevant to disability studies. First, care ethics

challenges moral systems built upon independent, rational individuals by insisting that primary moral knowledge is gained through the relationships we build with those dependent upon us and upon whom we depend. An ethics of care demands that dependencies be considered central, not marginal, to conceptualizations of social justice.

Second, care ethics challenges rationalist frameworks by insisting that some emotions, such as sympathy, empathy, and even anger—especially against social oppression—are essential to developing moral knowledge. As Held (2006) has argued, “The ethics of care... typically appreciates the emotions and relational capabilities that enable morally concerned persons in actual interpersonal contexts to understand what would be best” (pp. 10-11). In other words, emotion and rationality allow people to make the most effective ethical decisions. Furthermore, the ability to understand and appreciate others’ emotions, especially in response to specific asymmetries in power or access to resources, enhances one’s ability to successfully evaluate specific ethical situations.

Third, drawing from feminist traditions more broadly, the ethics of care reconceptualizes long-standing notions of the private and public. Traditional moral theories have concentrated on the public, contractual domain, where abstracted equals enter into consensual agreements. This framework neglects the moral issues found within domestic, intimate, and familial locations. Care ethics insists that these so-called private arenas are part of the social fabric, and that social justice theories must also consider relations that are involuntary, asymmetrical, and non-contractual by nature.

The concepts listed above can be discussed in some depth as problematic binaries set up by traditional ethical theories, in which one element is always privileged over its contrastive other: independence over dependence; reason over emotion; and the public over the private. In addition, as the perspectives of women with disabilities are presented throughout the semester, students witness how disability complicates and expands the scope of care ethics. As one example, while feminist theories of care have established a space for theorizing about the subjectivity and objectivity of caregivers and those dependent upon care, women with disabilities too often are positioned in the static role of *dependent*. Morris (2001) has critiqued feminist research focused upon “carers and their dependents,” because it has repeatedly “resulted in disabled and older women being excluded from the category of ‘women’ and classed as ‘dependents’ whose existence [is] a threat to non-disabled women’s economic opportunities” (pp. 6-7). As many women with disabilities have attested, this assignation of dependency subsumes all other identities, and locks them into objectified, passive positions that grossly misinterpret their complex relationships with care providers and the myriad other people in their lives.

As we consider disabled women’s experiences within an ethics of care, two feminist philosophers emerge as key to the discussion because both have taken the needs and demands of people with disabilities seriously in their theories of social justice. In the anthology entitled *The Subject of Care* (2002), the essays by Kittay and Nussbaum provide an interesting dialectic around an ethics of disability. The pioneering work of Kittay (1999; 2002) has challenged philosophy to take seriously the concerns of people like her daughter Sessa, who have significant cognitive and physical impairments. Following feminist traditions, both authors cogently critique

liberalism's failures to include people not classified as independent, rational, or self-sufficient, but whereas Kittay (2002) wonders if liberalism itself must be renounced, Nussbaum (2002) attempts to reconfigure a liberalist model to include the broad continuum of human *capabilities*. While it is beyond the scope of this paper to detail these arguments, I will sketch a few key ideas that students are encouraged to contemplate at greater depth.

In her essay, "When Caring is Just and Justice is Caring," Kittay (2002) has suggested that people with significant intellectual impairments may actually pose a limit to liberalism's ability to theorize human political interaction. She uses the example of her daughter Sesha, who cannot speak for herself, to demonstrate the descriptive limits of personhood within a liberal framework. In order for Sesha's voice to be heard, she needs an advocate, someone relationally committed to understanding what she communicates. Kittay (2002) has posited that a model based on relationships, not rationality, would better account for the unique needs, joys, and profound contributions made by her daughter: "Seeing Sesha in her interactions with those who care for—and about—her reveals that being a person has little to do with rationality and everything to do with *relationships*—to our world and to those in it" (p. 266).

In accounting for dependencies, she thinks seriously about both the caregiver and the person needing care. She sees such relationships as complex, with profound interdependencies, but also as asymmetrical and not reciprocal in the ways that contractual liberalism demands. Acknowledging these intricacies, Kittay has put forward a theory of care that attempts to consider the interests of the cared for and the carer—while also being attentive to not putting these in absolute competition with one another. She has reformulated care as a multifaceted concept—"a labor, an attitude, and a virtue" (2002, p. 259). If all of these elements are not encouraged, if an attitudinal commitment is not made, or if the carer feels unappreciated or exploited, the quality of care and the relationships will inevitably suffer. In effect, she worries that neither the caregiver nor her (or his) charge is well represented under liberal theories. Quite the opposite, in fact, caregivers are often saddled with the stigma already attached to people with cognitive impairments. As Kittay (2002) has submitted quite pointedly:

"If we want to remove the prejudice and lack of understanding that blights the lives of people with mental retardation, we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do). To do this we need to provide caregivers with conditions that allow them to do their work" (p. 270).

Ultimately, she argues that any ethical thinking must integrate asymmetrical dependencies to push all of us toward acknowledging our very real dependencies on each other. She does not want to abandon working toward independence, liberty, and autonomy as goals, but sees an integration of dependencies as essential to reconfiguring our ideas and misconceptions about these terms as absolute ideals.

Nussbaum's (2002) essay, "The Future of Feminist Liberalism," takes the commitment to asymmetrical dependencies seriously, but argues that liberalism can be reconfigured to integrate the full range of human capacities. As discussed earlier, she develops important critiques of liberal philosophical traditions that assume active participation among independent actors. She discusses Rawls' (1971) theory of social justice at some length, because although he

acknowledges dependencies as part of the human condition, he still sets these aside as unusual and extreme. Like many feminist theorists (Kittay, 2002; Held, 2006; Morris, 2001), Nussbaum (2002) disagrees with this exception, and argues that dependencies, which are elemental to human life, must be integrated into any viable theory of justice.

In order to do this, Nussbaum (2002) has suggested expanding the political conception of the person and the idea of human dignity to include “the dignity of mentally disabled children and adults, the dignity of the senile demented elderly, and the dignity of babies at the breast” (p. 193). By including these and all other human subjects in the foundational framework of social organization, we are more inclined to develop just and caring communities and institutions. She argues that by developing a theory of justice based upon human capabilities, in all their range and diversity, and the social obligations to support those capabilities, we would of necessity develop a different matrix for designing social systems.

As these two philosophers are put into conversation with one another, several questions emerge. We might ask, for example, if there is an implicit danger in Nussbaum’s (2002) language of capabilities. Does it return us to ideals of ability and rationality? Does her framework draw lines of exclusion or stigmatize differences, even as it attempts to address these concerns? Students might also discuss whether Nussbaum’s critique—that Kittay’s (2002) rejection of liberalism would result in the state becoming a “universal mother” (2002, p. 195) has merit. On the other hand, we ask if Kittay (2002) helps us imagine a more nurturing state, one whose responsibilities extend to the private domain of dependencies, interdependencies, and relationships. In such discussions, as students explore the strengths and potential pitfalls of a feminist ethics of care along with Kittay’s (2002) and Nussbaum’s (2002) elaborations of these theories, they become engaged in some of the exciting ways disability has begun to transform how scholars are thinking about justice, care, and social structures.

Centering Disability in Human Rights Discourse

Students in the undergraduate minor are required to complete an upper division course entitled Supports and Services prior to doing their practicum, where they will work directly with people with disabilities in locations such as non-profit providers, schools, state agencies, or advocacy groups. This final on-campus course provides students with practical information about how social service systems, direct support, and disability policies have been structured, and how some of these have changed in response to disability rights and advocacy over the last few decades. In order to give students a wide range of perspectives, professionals, policy experts, and people with disabilities from a variety of fields present topics to the class. Throughout the semester, we draw upon ethical theories and debates introduced in previous courses to develop disability studies questions, critiques, and analyses of the professions and services we discuss. In one of the cornerstone assignments, students assess the ethical codes or guidelines of their own fields or professions, and suggest specific ways that disability perspectives might be more fully incorporated.

While the bulk of the curriculum focuses upon systems and policies in the U.S. and U.K., students are also exposed to selected international activist efforts and service models, so they can

begin to compare different frameworks, and discuss what might be learned from alternative approaches. Within this more global context, we connect the conversation around ethics and social justice to an international discourse of rights and vulnerabilities. Turner (2006) has taken up the complex intersections between disability and universal rights in *Vulnerability and Human Rights*, so this text provides a framework for the class to consider how the demands for equality, accessibility and integration made by disabled people parallel those of other groups. Turner (2006) argues that as we witness global injustices, state sanctioned human rights abuses, and widespread human suffering, scholars need to pay attention to the issues that connect people across cultures, rather than to avoid the most difficult international conflicts in the name of cultural relativism. From this perspective, he builds a philosophical framework of ethics around embodiment, shared vulnerabilities and precariousness, which relates in key ways to care ethics, but moves the discussion from personhood, autonomy, and care relationships to one of universal rights.

By focusing more on commonalities than differences, Turner (2006) has suggested a model that attempts to unite people across cultures through shared ethical commitments to challenge injustices:

“While humans may not share a common culture, they are bound together by the risks and perturbations that arise from their vulnerability... This need for ontological security provides a strong moral argument against cultural relativism and offers an endorsement of rights claims for protections from suffering and indignity” (p. 9).

He stresses that most social formations, from family networks, community organizations, and educational systems, to health institutions, businesses and governments, have emerged in response to shared vulnerabilities and the precariousness of environments. These structures provide evidence of the natural bonds of human connectedness, shared dependencies, and social solidarity—not autonomy, self-sufficiency, or mythic independence.

In his conceptualization of individual and social development, Turner (2006) has delineated three essential processes that integrate disability experience into the broad continuum of the natural human experience: “embodiment,” “enselfment,” and “emplacement” (p. 27). In this construct, enselfment is the self-reflective process by which we understand how our bodies and our place in the world intersect. That is to say, whatever is enacted upon the body, be it pleasure, pain, or suffering, is also experienced and given meaning through one’s thoughts, cultural location, economic reality and so forth. This process of enselfment—of reflecting upon how one’s embodiment, cognitive capacity, economic status, ethnicity, gender, sexual preference, or personal aesthetic has influenced one’s social standing, is a key element in identifying human rights abuses, and recognizing or advocating for essential supports.

Well versed in the social model of disability and the failures of modern welfare states to adequately serve the needs of disabled citizens, Turner (2006) frames his human rights model around vulnerability and embodiment specifically to address these exclusions from the outset. He has argued that because citizenship has been so fraught with inequities, unfair entitlements, and exclusions, “the language of human rights is ultimately the only plausible language for expressing the needs of people with impairment and disability” (2006, p. 90). He also suggests

that vulnerability provides a language for embodiment that the strong social model has rendered invisible. In other words, a discourse around shared vulnerabilities will both include disabled people and provide a language for the phenomenology of impairment. By speaking of shared rights and vulnerabilities, the concerns of disabled people are integral to an understanding of justice and injustice—rather than being deferred indefinitely as a complication.

In outlining Turner's (2006) human rights model at some length, I have intended to highlight one interesting theoretical approach to global issues that takes the critiques of disability studies scholarship seriously. Turner (2006) also enters into the ethical terrain developed in previous classes from a different direction, which provides ample material for discussion. After students have considered many theories foregrounding dependency and care, we can ask whether shared vulnerabilities really offers more traction than shared dependencies. Students are also encouraged to think about the limits of civil rights claims, and whether global rights discourse actually promises greater integration of disability. On the other side, even if it does offer a better framework for inclusion, how would this help people with disabilities who need to address issues at a local or national level? After considering these and many other questions, and looking at the ethics of disability from a variety of perspectives, students are better equipped to consider the ethical questions that may emerge in their own fields and professions with greater critical depth and skill.

Conclusion

As the meanings around disability continue to be haunted by exclusionary notions of human dignity, citizenship, and capacity, the field of disability studies will be engaged in rigorous ethical debates, many of which center around urgent liberties such as rights to life, reproductive freedom, and bodily integrity. Acknowledging the crucial nature of such public discourse, we have attempted to scaffold specific ethical components across our undergraduate minor in disability studies, in order to allow students to deepen their knowledge of ethical traditions, and understand how disability perspectives challenge and transform them. In considering the ethics of disability explicitly, students are encouraged to examine their own values, principles, and intellectual commitments, practices that will help guide the development of their own research questions, and provide them with skills to approach the complex moral and ethical issues they will inevitably encounter in the years to come.

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Endnotes

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