What Remains Unsaid:

Confronting the Ethical Turn in Disability Studies

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Abstract: This paper examines what I identify as the ethical turn in disability studies; namely, the recent emphasis on reimagining disability as a universal category that invites a heightened sense of obligation to the disabled Other. Notwithstanding the value of acknowledging vulnerability and dependency as aspects of the human condition, I argue that this approach does not fundamentally alter the way we already think about disability, nor does it address the very real inequalities experienced by individuals with disabilities. In order to understand why this appeal to a common humanity is so problematic, I draw upon Hannah Arendt’s critique of the devastating role of compassion in the French Revolution. Rather than reframing disability as universal category of which we are all potential members, I turn instead to Arendt’s concept of representative thinking. Specifically, I examine whether an Arendtian approach to the imagination can offer a new way of thinking about disability, particularly more severe forms of cognitive and physical disability. Against the belief that disability is unimaginable for able-bodied individuals, I see in representative thinking the possibility of opening up a space in which we can consider disability without recourse to a predetermined concept of what disability necessarily is*.*

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1. Introduction: A Pathetic Event

The problem is that the story is too simple, I think. I have learned that in real life, there are more twists and turns. The black is not entirely black, and the white turns out to be a different color entirely. There are never only two choices. I am trying to find a new story, but I am finding it hard. It takes too long to explain it all, and I keep on losing the thread. I am sure it would be easier if I just told the old story. Many people still like it, certainly. But how can I tell a story if I am not certain it is true? Of course, this is not a true story either. But that’s different.

- Tom Shakespeare[[1]](#footnote-1)

On March 12, 1990, nearly 1,000 disabled individuals converged on Capitol Hill to protest delays in the passage of the Americans with Disabilities Act (ADA). The legislation had passed the Senate in September 1989 but remained stalled in the House despite widespread bipartisan support.[[2]](#footnote-2) At the end of the demonstration, around sixty protestors affiliated with American Disabled for Accessible Public Transit (a militant, direct action group better known as ADAPT) got out of their wheelchairs and attempted to climb the steps of the Capitol.[[3]](#footnote-3) Photographs from the “crawl-up” mostly focus on Jennifer Keelan, an eight-year-old with cerebral palsy who crawled to the top of the stairs on her elbows and knees. This was not Keelan’s first protest. She had been arrested a year prior while attending a similar ADAPT protest in Montreal.[[4]](#footnote-4) The photograph of Keelan reaching the top of the stairs was, according to Joseph Shapiro, “the one…image from the ADA fight to register in public memory.”[[5]](#footnote-5)

While the crawl-up did succeed in attracting the attention of the media—which until then had provided scant coverage of the passage of the ADA—many within the disability rights community were critical of ADAPT’s employment of what were perceived to be demeaning and stereotypical images of disabled individuals.[[6]](#footnote-6) The *Disability Rag*, a prominent disability rights publication, commented: “One might question why a movement intent on showing that disabled people are adults, not children, would make their central media image a child.” Why, they wondered, “was everyone being so inarticulate?”[[7]](#footnote-7) According to these critics, the “grueling” crawl-up had “conveyed precisely the image disabled people wanted to avoid—of being pitiable, inspirational, and childlike.”[[8]](#footnote-8) Echoing these sentiments was *Washington Post* ombudsman Richard Harwood, who—in response to a reader’s complaint that the paper had not sufficiently covered the occasion—dismissed the crawl-up as a “pathetic event” not worthy of further editorial comment.[[9]](#footnote-9)

I return to this image—now over twenty years old—not to revisit the controversy surrounding ADAPT’s confrontational tactics, but rather because I see it as emblematic of what is at stake in the current debates in disability studies and activism. The criticism of Keelan’s participation in the crawl-up (to say nothing of the perceived inarticulateness of its participants) expressed profound anxiety about how best to address the vulnerability of individuals with disabilities in ways that did not simply confirm long-held stereotypes about their presumed “child-like” status. For many disability activists, ADAPT’s tactics seemed to run counter to the political goals of the disability rights movement and the demand for “equality of opportunity, full participation, independent living, and economic self-sufficiency” for people with disabilities.[[10]](#footnote-10)

Emphasizing the importance of the ADA, Randy Jennings, a member of the National Rehabilitation Association—who was also present at the protest but did not participate in the crawl-up—commented: “’This bill is the most significant piece of legislation to come along for disabled people in a long time…We’ll see people in chairs going to the opera. They’ll be sitting with us in the same ballpark…And for the first time we’ll all be able to go together.’”[[11]](#footnote-11) What activists like Jennings did not want to acknowledge, however, was that this demand for “equality of opportunity, full participation, independent living, and economic self-sufficiency” could only be voiced on behalf of *some* members of the disabled community. For others—particularly those with more severe cognitive and physical disabilities—these goals remained impracticable.

In one sense, imagining disabled individuals as “people in chairs going to the opera” assuages the anxiety and discomfort provoked by the image of Keelan crawling up the Capital steps. Theirs is a familiar sight, if altered somewhat by the use of a wheelchair. And yet, I want to resist the urge—so prevalent in disability studies and activism—to view the stark contrast between these images as requiring a choice between two competing—if not contradictory—narratives of disability. According to this view, either we accept the mantle of bourgeois respectability offered by the (presumably articulate) wheelchair-using operagoers, or we confront the vulnerability exposed by the participants of the crawl-up—we cannot have both.

What would it mean to consider these images alongside each other, not as symmetrical—and therefore the same—but as equally valid representations of what disability is?[[12]](#footnote-12) Put differently, how might we account for the seemingly incommensurable differences between disabilities without thereby reducing these differences to a unified category that can, in the words of Tom Shakespeare, “explain everything?”[[13]](#footnote-13)

Within disability studies, the attempt to get at a clear understanding of what disability *is* has taken on paramount importance. Not surprisingly, this has resulted in a fierce debate over who gets to define disability and on what grounds. According to Susan Wendell, “we encounter the problem of definition as soon as we take an interest in disability.”[[14]](#footnote-14) Any attempt to arrive at an understanding of what disability “really is,” almost immediately confronts problems of exclusion. Are we talking about physical or mental disabilities? What about chronic illness, injury, learning disabilities, deafness, and the physical limitations of aging—are these disabilities? Where do we draw that line, and perhaps most importantly, *who* gets to draw that line?

Absent a stable and coherent definition with which to unify what is otherwise a disparate assortment of intellectual and physical conditions, a number of theorists have suggested a different approach that takes disability as its starting point.[[15]](#footnote-15) Rather than consider disability as a “deviation from a presumed normal center,” this approach reverses this construction such that *disability* becomes the rule rather than the exception.[[16]](#footnote-16) On this view, an awareness of the ways in which we are all dependent on others calls into question the boundaries that render disability as ability’s unimaginable other. Insofar as disability is characterized by a heightened dependency on others, so the story goes, then we are *all* potentially disabled. Far from occupying the space of the “radically other,” then, disability becomes a universal category of which we are all members.[[17]](#footnote-17)

In this paper, I examine what I identify as the “ethical turn” in disability studies; namely, the recent emphasis on reimaging disability as a universal category that invites a heightened sense of obligation to the disabled Other (who is also, potentially, one’s self). Notwithstanding the value of acknowledging vulnerability and dependency as aspects of the human condition, I argue that this approach does *not* fundamentally alter the way we already think about disability, nor does it necessarily address the “unease around questions of human frailty,” that disability is said to provoke.[[18]](#footnote-18) However valuable an ethics grounded in the acknowledgement of vulnerability and dependence might be in thinking differently about disability, it has so far failed to connect this ethical practice to collective action. It is more often the case that disability becomes “good to think”[[19]](#footnote-19)—useful to the extent that it enables what Lauren Berlant calls an “aesthetics of compassion—the cultivation of the senses toward a more nuanced and capacious engagement with scenes of human activity.”[[20]](#footnote-20)

I will begin by providing a brief overview of recent developments in disability studies in order to better understand what precipitated this ethical turn and why it has appeared as a plausible alternative to earlier models of disability. I want to be clear that what I refer to here as the ethical turn in disability studies is not always recognized as such; nor, I imagine, would some of the theorists mentioned in this paper necessarily agree with my characterization of their work.[[21]](#footnote-21) What I identify as the ethical turn is not a unified approach to disability along the lines of the social or medical model of disability. Rather, it weaves together a number of different strands of disability studies loosely organized around the notion of disability as a universal category that invites us to consider the vulnerability and dependency of disabled individuals as a condition we all share.

After laying this groundwork, I will proceed by considering the ethical turn in greater detail, focusing specifically on the assumptions and exclusions that undergird this approach. This analysis is informed by critiques of the ethical turn in political theory, where it has received more sustained critical attention. In considering these other critiques, I view these two “turns” as parallel, with both tending to privilege experiences of vulnerability and dependency as common to all human beings. In order to understand whythis appeal to a common humanity is so problematic, I turn to Arendt’s critique of the “devastating” role of compassion in the French Revolution found in *On Revolution.*[[22]](#footnote-22)Revisiting Arendt’s views on compassion allows for a more sustained consideration of the ways in which this turn achieves commonality by leveling important differences between individuals such that the “worldly space between men where political matters…are located” is “abolished” (*OR,* 76).

Finally, I will consider how we might approach disability differently such that we are able to take into account those disabilities—particularly more severe forms of physical and cognitive disability—that have typically been overlooked in disability studies. Rather than reframing disability as “‘universalizing discourse’ of difference,” I turn instead to Arendt’s practice of “training the mind to go visiting.”[[23]](#footnote-23) Specifically, I want examine whether an Arendtian approach to the imagination and what she refers to as “representative thinking”— understood here as a process through which we “mak[e] present to [our] mind the standpoints of those who are absent”—can offer a new way of thinking about disability.[[24]](#footnote-24) In the end we might agree with Anita Silvers that “the opacity of disabled people’s experience” renders representative thinking “ineffective where persons with disabilities are concerned.”[[25]](#footnote-25) However, I want to challenge the widely held perception that disability presents the limit-case to the ability to be and to think where we actually are not. Against the belief that disability is simply “unimaginable” for able-bodied individuals, I see in representative thinking the possibility of opening up a space in which we can consider disability without recourse to a predetermined concept of what disability necessarily *is.*

That said, I take seriously the dangers of the imagination in the case of disability, and will consider an example where able-bodied individuals were called upon to imagine themselves as disabled (with disastrous consequences). Rather than whole-heartedly endorsing representative thinking, then, I am somewhat more reserved in my enthusiasm. Like Arendt, I believe that representative thinking requires a certain amount of strength; a willingness to, in her words, “put that which is too close at a certain distance so that we can see and understand it without bias and prejudice.”[[26]](#footnote-26) Whether this ability to “see things in their proper perspective” is possible in the case of disability is certainly a matter for further discussion.[[27]](#footnote-27) Nevertheless, I see it as a possible avenue from which we might begin to tell not a “new story,” but rather, *stories*, about disability.

1. Confronting the Ethical Turn

According to the 2010 Annual Disability Status Report, the poverty rate among non-institutionalized, working-age disabled adults in the United States is 27 percent (compared to 11.9 percent for those without disabilities).[[28]](#footnote-28) While there has been a strong emphasis on inclusion and deinstitutionalization for those with more severe disabilities, this remains both practically and financially out of reach for many who rely on Medicaid for access to services. In the words of Harriet McBryde Johnson, a disability rights lawyer with spina bifida, even those individuals who live independently with the help of attendants “live on the edge of the disability gulag.” Says McBryde Johnson:

I knew my family wasn’t like F.D.R’s or Helen Keller’s; they didn’t have the means to set me up for life. I was more like one of my girlfriends, who had lived with nice parents in a nice house with a nice hired lady to take her to the park to meet me and my lady—until something went wrong and she disappeared into Coastal Center. Whenever my parents scrambled to pay for something unexpected, a part of me saw my freedom hanging in the balance. I learned early that privilege doesn’t always last. [[29]](#footnote-29)

McBryde Johnson’s fear is well founded. In July 2007, Jonathan Carey, an autistic 13-year-old living at the Oswald D. Heck Developmental Center in New York, died of asphyxiation after being forcefully restrained by an employee of the Center in the back of a van.[[30]](#footnote-30) Jonathan was placed in the Center after he became too difficult for his parents to care for at home. This situation is not uncommon. Those without the financial means to support in-home care or smaller group living arrangements often end up in large state institutions staffed by underpaid and overworked attendants, and allegations of abuse and neglect are frequent.[[31]](#footnote-31)

I offer these accounts of the “disability gulag” not to encourage what Catherine Prendergast has called a “pathetic reading” of disability, but rather because they throw into sharp relief the inadequacy of an ethics founded on the idea that we are all only temporarily able-bodied.[[32]](#footnote-32) It is one thing to say, as Robert McRuer observes, that “everyone is virtually disabled,” but it is quite another to confront the kind of fear and powerlessness that comes with “living on the edge of the disability gulag.”[[33]](#footnote-33)

In this section, I examine what I identify as the ethical turn in disability studies, understood here as an ethical orientation toward the (disabled) other that arises out of a heightened awareness of one’s own vulnerability and dependency. I will begin by providing an overview of the story—or, rather, stories—that disability studies tells about disability. This account begins with the social model—what Tom Shakespeare refers to as the “good,” “simple” story that “explains everything”—and the “bad,” “tragic” story provided by the medical model. I will then consider what I take to be the foundation of disability studies’ ethical turn; namely, the increasing tendency to view disability as an aspect of human variation grounded in mutual experiences of vulnerability and dependency. While the social model is, according to Shakespeare, an “old story,” I want to be careful not to overemphasize this distinction between “old” and “new” stories. To do so would be to imply a false unity in what is a variety of intersecting approaches. Instead of approaching this emphasis on the universality of disability as if it were a “new story,” then, I regard it as a response to—and, in certain respects, a continuation of—the social model.

I will proceed by considering the claim—made by an increasing number of disability scholars and activists—that we are all only temporarily able-bodied. Pushing upon these observations, I argue that the concept of temporary ability does *not* challenge able-bodied individuals to shift their conception of disabled individuals. It is more likely that, when invited to consider periods of heightened vulnerability and dependency *as* disabilities, able-bodied individuals will simply reflect on their own condition. This misleads us into believing that we are opening ourselves to a more responsive engagement with disabled individuals, when in reality, little has changed. Without substantively challenging able-bodied individuals to think differently about disability, then, it becomes difficult to understand how this recognition of our temporary ability can cross the conceptual abyss between the transgressive potential of this designation and the worldly engagement necessary to inspire collective action.

*Old and New Stories*

But first, the social model of disability—that “old,” “simple” story that “explains everything.” According to this view, disability is a socially constructed phenomenon that does not find its foundation in the body, but rather in the built environment and culturally defined notions of the normal and the abnormal body. Much of the work in this area has focused on the reclamation of the disabled body from a medical or biological model that views disability as an individual disorder best managed, if not alleviated or cured, by medical intervention.[[34]](#footnote-34) Against the individualizing tendencies of the medical model, theorists in this tradition have tended to view disability studies as an emancipatory practice that, in the words of Rosemarie Garland-Thomson, “strives to rewrite oppressive scripts.” Insofar as disability is a category that is *imposed* on non-normative bodies, disability becomes “a system of representation that marks bodies as subordinate, rather than an essential property of bodies that supposedly have something wrong with them.”[[35]](#footnote-35)

While this approach has provided a powerful standpoint from which to challenge the continued exclusion and stigmatization of disabled individuals, by assuming that the goal of disability studies and activism should be a “fully enabling construction of [disabled] identity,” it has been unable to address those aspects of disability that most resist positive resignification.[[36]](#footnote-36) It is, to use Shakespeare’s terminology, “too simple.” It assumes a world in which, if all barriers to access were removed and disability were no longer seen as abnormal, disability as a category would cease to exist. While this is certainly a hopeful possibility, the relative clarity and simplicity of this approach—its ability to “explain everything”—rests on several (often unstated) assumptions.

First is the tendency to privilege physical disabilities over cognitive disabilities, “perpetuating,” as Licia Carlson argues, “a form of essentialism that draws a sharp division between the *cognitively* able/disabled.”[[37]](#footnote-37) Insofar as the social model considers the problems associated with disability to be primarily structural and attitudinal, it cannot account for those disabilities that no amount of accommodation can render insignificant. As Margrit Shildrick notes in her powerful critique of the social model: “The social model of disability unwittingly perpetuates a historical pattern of disavowal. It is not simply that the model appears to devalue the phenomenology of embodied difference, such that issues of pain, desire, and affect are rarely incorporated, but that the emphasis is complicit in the denial of difference.”[[38]](#footnote-38)

While I agree with Shildrick, I believe that the problems with the social model extend beyond what is implied by this “denial of difference.” When scholars like Garland-Thomson attempt to “reimagine disability” by “probing the cultural meanings attributed to bodies that societies deem disabled,” they assume that the negative valences of disability can best be dealt with by troubling the binary that maintains disability as ability’s abject other.[[39]](#footnote-39) This is not, in itself, problematic. The issue here is not so much one of *difference*—whether the social model can accommodate the full range of disabled experience—rather, it concerns the contradiction contained in the desire to “reimagine disability” as a positive identity.[[40]](#footnote-40)

If taken to its logical conclusion, viewing disability as the product of social stigma and barriers to access would seem to suggest that the removal of these barriers would render the category of disability (as that which is opposed to ability) meaningless. Assuming, for the sake of argument, that such a radical restructuring of the public sphere were in fact possible, this presents a paradox. Having evacuated disability of its negative connotations by suggesting that the difference that disability poses is primarily structural and attitudinal, how then are we to go about reinscribing disability as an empowered identity? Not only does such an identity rest on a sharply circumscribed understanding of what disability *is—*namely, physical, non-progressive and pain-free*—*but it can only claim community on behalf of an abstract notion of bodily difference.

*Navigating Temporary Ability*

Recognizing the limitations of the social model, a number of theorists (including Garland-Thomson) have suggested an approach that disrupts the ability/disability binary by calling attention to the instability of *all* bodies.[[41]](#footnote-41) On this view, an awareness of the permeability of the category of disability—the fact that one could, for example, become paralyzed tomorrow as a result of a car accident—prompts a radical rethinking of the able-bodied norm against which disability has been measured. In one sense, identifying non-disabled individuals as only *temporarily* able-bodied emphasizes the extent to which ability is, at best, an unstable—rather than fixed—state. Not only does disability change over time, but we are all, through aging or illness, eventually going to be disabled. Following this logic, disability becomes, as McRuer puts it, the “one identity category that all people will embody if they live long enough.”[[42]](#footnote-42) Far from occupying the space of the radically other, disability emerges as a universal category of which we are all (potential) members. This “new kind of universalism,” says Lennard Davis, “aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence.”[[43]](#footnote-43) What distinguishes the able-bodied from the disabled, becomes, in this view, a matter of *perspective*, of reorienting our world-view such that we become more attentive to the various points of dependency that are otherwise not readily apparent—a way of seeing disability where we previously only saw ability.

Any account of disability, if it is to be at all realistic, *must* acknowledge dependency and vulnerability. Consequently, I want to make it clear that my issue is not with the renewed attention to vulnerability and disability *per se,* but rather with the centrality of their role in linking ability and disability. When scholars like Davis, Garland-Thomson, and McRuer suggest that we are all only temporarily able-bodied, they often draw attention to aspects of the human condition in which the experience of dependency and vulnerability is more pronounced, but not so obvious as to be “out of the ordinary.” Insofar as we are asked to consider the “disability to come,” then, this often takes the form of recognizing socially accepted periods of dependency and vulnerability—such as infancy or old age—*as* disabilities (McRuer 2006, 208). Says Tobin Siebers,

Most people do not want to consider that life’s passage will lead them from ability to disability. The prospect is too frightening, the disabled body, too disturbing. In fact, even this picture is overly optimistic. The cycle of life runs in actuality from disability to temporary ability back to disability, and that only if you are among the most fortunate, among those who do not fall ill or suffer an accident.[[44]](#footnote-44)

While I largely agree with Siebers that the “prospect” of disability is “frightening” for non-disabled individuals, I do not believe that the failure to recognize that “the cycle of life runs…from disability to temporary ability back to disability” is necessarily due to fear. Rather, I worry that by calling upon what might be thought of as “ordinary” life events (infancy, for example) and reimagining them *as* disabilities, we are absolved from considering the very real problems confronting individuals with already-existing disabilities. In other words, by seeing disability where we previously only saw ability (infancy, old age), we are reassured that we have taken sufficient steps to, as Siebers puts it, “overturn the dominant image of people with disabilities as isolated victims of disease or misfortune,”[[45]](#footnote-45) without truly confronting the frightening prospect of disability as it is already lived. What McRuer refers to as the “disability to come” provides a fairly nonthreateningalternative to considering the kind of scenarios with which I opened this section. Approaching disability in this way allows us to subordinate the threat of already-existing disabilities to the promise of “making [disability] seem ordinary,”[[46]](#footnote-46) “perform[ing],” as Lauren Berlant puts it, “the evacuation of significance from actually-existing subjects” such that these disabled “’others’ are ghosted for a good cause.”[[47]](#footnote-47) In other words, we can consider “the disability to come” without having to take seriously what it might mean to “live on the edge of the disability gulag.”

This is not to say that disability studies should *not* be actively engaged in challenging the binaried construction of able-bodied versus disabled individuals. Indeed, drawing attention to the instability of the disability/ability binary has been a powerful tool in questioning the autonomous, rational subject at the heart of liberal democratic theory. However, I am not convinced that an awareness of what Shildrick refers to as “the contingency and incompletion that characterizes all life” provides a sufficient basis for addressing the very real vulnerabilities to which disabled individuals are disproportionately exposed.[[48]](#footnote-48) Rather, I worry that this turn toward ethics—an awareness of our mutual vulnerability and dependency—insulates us from, rather than exposes us to, the reality of disability.

What is demanded by this turn is *not*, I argue, a “shift in our understandings of flourishing, social justice, and embodiment;” rather, it is an appeal to a common humanity achieved via a compassionate regard for the disabled Other.[[49]](#footnote-49) This is not immediately evident—in part, I imagine, because the term “compassion” is so little used in disability studies (the distance between compassion and pity being far too short). In order to better understand how compassion operates in these discourses, then, I turn to the thought of Hannah Arendt, whose analysis of the influence of compassion on the French Revolution helps to illuminate why the claim to a common disabled identity is both politically misguided and potentially dangerous. For, as Arendt reminds us, “compassion…abolishes the distance, the in-between which always exists in human intercourse” (*OR,* 76), and it is this in-between that is necessary for action—and therefore, politics—to occur.

*Against Compassion*

In her analysis of the “devastating” role of compassion in the French Revolution in *On Revolution*, Arendt notes that the American Revolutionaries, unlike their French counterparts, did not have to confront the mass poverty that so confounded and entranced figures like Robespierre and Rousseau (62). Undistracted by the misery and want of *les* *malheureux,* they could remain committed to the achievement of freedom necessary for the foundation of the republic. The French Revolutionaries, on the other hand, were faced with a people whose conditions, despite the fall of the monarchy, remained very different from their own. Lacking a common cause through which to unite these disparate groups, it was compassion—what Robespierre referred to as “’that imperious impulse which attracts us towards *les hommes faibles*’”—that served to temporarily bridge this chasm (65).

This harnessing of compassion for political purposes is problematic for several reasons. The first is what Arendt identifies as compassion’s tendency to “abolish” the worldly space between individuals necessary for collective action. Compassion—the capacity to *feel with* suffering others—demands that what unites individuals is *not* a common cause (the foundation of freedom, for example), but rather a common sentiment—a feelingwith a tenuous (if not downright dangerous) relationship to practice. “It is not compassion,” Arendt reminds us, “which sets out to change worldly conditions in order to cease human suffering” (*OR,* 77).

And yet, the problem with compassion is not simply that it is incapable of inspiring or guiding action. To dismiss compassion as politically “irrelevant and without consequence”—as Arendt seems to imply in a section of *On Revolution—*would be to miss the more insidious dangers against which she is otherwise warning her readers (76). Here, we might consider instead her characterization of the misery and suffering of *les malheureux* as an engulfing tide that, when combined with the “ocean-like sentiments it aroused...drown[ed] out the foundations of freedom” upon which the success of the Revolution depended (85). That these oceanic metaphors echo what she describes in the *Human Condition* as the “submersion” of the private and public realms in the social is no coincidence (69). Indeed, the “magic of compassion” is precisely this “boundless” capacity to overcome barriers (*OR*, 80). What seems at first to provide the answer to the vast inequalities confronting the French Revolutionaries belies an almost violent disregard for the worldly in-between that acts to bind individuals in a common cause.

Compassion, as Carrie Sandahl reminds us, “is only a step away from pity, and it is impossible to equal someone who pities you.” [[50]](#footnote-50) While it is unlikely that any of the theorists I have discussed in this section would disagree with Sandahl on this point, there are nevertheless a number of similarities between the desire to understand disability as “the most universal of human experiences”[[51]](#footnote-51) and what Arendt identifies as compassion’s tendency to reduce those “many voices and differences in opinion” to an object of compassionate concern (*OR*, 94) The problem here is not simply that this desire for universality performs “the evacuation of significance from actually-existing subjects,” as Berlant suggests, but that it distracts from a vision of politics as what Linda Zerilli refers to as a “world-building practice.”[[52]](#footnote-52) Understanding politics as a “world-building practice” reminds us that what is at stake in disability politics is not (or, not necessarily) a matter of articulating a more expansive understanding of disabled identity such that we become more aware of—and responsive to—human conditions of vulnerability and dependency. Rather than trying to achieve the impossible task of arriving at a definition that could explain once and for all what disability is (and how best deal with it), Arendt forces us instead to “think without being taught a doctrine.”[[53]](#footnote-53) To confront, in other words, the “frustrations and fragility of action” without the guarantee of an ethical response (*OR*, 88).

1. Conclusion: Confronting Disability

Earlier in this paper, I asked what might it mean to give an account of those “other things that are unsaid” about disability—to confront stories like Jonathan Carey’s or Harriet McBryde Johnson’s without flinching or turning away. I have argued that the ethical turn in disability studies has failed to accomplish this, despite the increased attention paid to vulnerability and dependency—issues that were largely left out of earlier approaches to disability. Rather, by suggesting that disability become a universal category of which we are *all* potential members, this ethical turn risks abolishing differences between individuals (both disabled and not) such that the very real inequalities experienced by disabled individuals become obscured. In this concluding section I want to suggest Arendt’s concept of representative thinking as a possible avenue for confronting those “other things that are unsaid.” While Arendt does not discuss disability, she has much to say on the topic of enduring and facing reality, and for this I believe her work deserves further consideration—both here and in disability studies more generally.[[54]](#footnote-54)

Given the risks that can result from imagining oneself in the position of a disabled individual, I approach Arendt’s concept of representative thinking by way of an example in which this practice failed miserably (with potentially serious consequences). For this, I consider the controversy surrounding the development of the Oregon Health Plan in the early 1990s, focusing specifically on an article by Anita Silvers, “Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities,” in which she argues that disability is simply “so different as to be unimaginable” for nondisabled individuals.[[55]](#footnote-55) In challenging this assertion, I consider how we might approach disability differently using Arendt’s concept of enlarged thought.

*The Oregon Health Plan and Experiential Inaccessibility*

The Oregon Health Plan was, according to Jonathan Oberlander, Theodore Marmor, and Lawrence Jacobs, “the first public insurance program to ration medical care explicitly, systematically and openly by denying coverage for health care services.”[[56]](#footnote-56) While the plan was lauded as a “pioneering effort” in the fight against rising healthcare costs, many objected to the use of a ranked list of covered medical conditions which, at one point in the plan’s development, ranked the treatment of thumb sucking above that of cystic fibrosis.[[57]](#footnote-57) The list was drawn up using scientific and non-scientific sources, including a telephone survey of able-bodied individuals in which they were asked to place themselves in the position of a blind person or a person in a wheelchair.[[58]](#footnote-58) The majority of respondents said they would rather be dead than face either of these conditions. These responses were factored into the final results such that “being impaired in *some* way that defie[d] medical restoration automatically reduce[d] one’s eligibility for *many kinds* of care” under the proposed plan.[[59]](#footnote-59)

For Silvers, the Oregon example exposes the limits of our imaginative capacity where disabilities are concerned, “magnify[ing] the impact of [disability’s] deficit” such that “our aversion to the very idea of being disabled forestalls our understanding the disabled from their perspective.”[[60]](#footnote-60) For participants in the health survey, the perceived threat of disability prevented them from arriving at anything other than what Stacey Clifford refers to as the “seemingly inevitable interpretation of [disabled individuals’] lives as tragic misfortunes.”[[61]](#footnote-61) Notwithstanding the fact that *actual* suicide rates among disabled individuals are much lower than the Oregon survey would suggest, the “inevitable interpretation of [disabled individuals’] lives as tragic misfortunes” led many participants to view suicide as the only legitimate response to a life spent in a wheelchair. It would seem, then, that the difference that disability poses renders it “so different as to be unimaginable,” as Silvers suggests.[[62]](#footnote-62) But what exactly does Silvers mean when she says that disability is “unimaginable?"

According to Silvers, there is a tendency to view disabled individuals “as being in a state *unthinkable* for oneself” (emphasis mine).[[63]](#footnote-63) This notion of disability as unthinkable is one I want to explore in greater depth. Throughout the text, Silvers refers to disability as that which is “alien,” “deviant,” and “abnormal,” appropriating derogative terminology to highlight the extent to which disability departs from that which is familiar.[[64]](#footnote-64) However, for something to be “unthinkable” suggests not a failure of imagination, but rather a lack of adequate knowledge such that what Arendt refers to as “being and thinking in my own identity where I actually am not” is rendered impossible.[[65]](#footnote-65) This would seem to agree with Silvers’s assessment that respondents to the survey were “far from accurate…in predicting the actual behavior of persons with disabilities,” “express[ing] myths about disability rather than empirically confirmable wants.”[[66]](#footnote-66)

Setting aside for a moment the details of the survey and its implications, I identify a number of problems with where Silvers draws the boundaries of our imaginative capacity. In the quote excerpted above, Silvers seems to suggest that imagining ourselves in the position of an other rests on our ability to “accurately estimate” their “actual behavior” and “empirically confirmable wants.” This stringent empirical requirement would seem to prevent us from *ever* imaginatively taking the position of someone else—disabled or otherwise. Indeed, in order for such a requirement to be satisfied, there would have to be what Iris Marion Young refers to (in her response to Silvers’s article) as “a relation of symmetry between self and other” such that differences in behavior and wants would be rendered insignificant.[[67]](#footnote-67)

While Young believes that this relation of symmetry is implied by Arendt’s concept of enlarged thought,[[68]](#footnote-68) I argue that this is not what Arendt has in mind when she speaks of imagination as that which “enables us…to be strong enough to put that which is too close at a certain distance so that we can see and understand it without bias and prejudice.”[[69]](#footnote-69) As Arendt specifies in her lectures on Kant’s political philosophy, “train[ing] one’s imagination to go visiting” requires the ability “to think critically” about “the prejudices and traditions one inherits” (*LKPP*; 43, 42). When respondents to the telephone survey responded that they would rather die than be blind or in a wheelchair, they failed to, as Kant put it, “abstract from the limitations which contingently attach[ed] to their judgments.”[[70]](#footnote-70) As a result, they remained limited by their own self-interest, trapped by their “merely individual idiosyncrasies.”[[71]](#footnote-71) As Arendt specifies:

“Enlarged thought” is the result of first “abstracting from the limitations which contingently attach to our judgment,” of disregarding its “subjective private conditions…by which so many are limited,” that is, disregarding what we usually call self-interest, which, according to Kant, is not enlightened or capable of enlightenment but is in fact limiting. The greater the reach—the larger the realm in which the enlightened individual is able to move from standpoint to standpoint—the more ‘general’ will be his thinking.[[72]](#footnote-72)

In this sense, Arendt would likely agree with Silvers that disability was “inaccessible” for *these* survey participants insofar as they remained “limited” by their “subjective private interests.” However, as Arendt observes, “train[ing] one’s imagination to go visiting” is a practice that requires leaving behind one’s subjective limitations and “learn[ing] from the “testing that arises from contact with other people’s thinking” (*LKPP,* 42). Here Arendt’s emphasis on “training,” “learning,” and “testing” is significant, pointing to an aspect of imagination that Silvers misses.

According to Silvers, “’normal’ individuals cannot accurately estimate what life would be like if placed in a ‘damaged’ individual’s place.” As she puts it, they just don’t “get it.”[[73]](#footnote-73) However, imagination, as Arendt views it, requires us not to “get it,” but rather to “be strong enough to put that which is too close at a certain distance so that we can see and understand it without bias and prejudice, to be generous enough to bridge abysses of remoteness until we can see everything and understand everything that is too far away from us as though it were our own affair.”[[74]](#footnote-74) Viewed in this light, the strength necessary to “see and understand without…bias and prejudice” offers a way of overcoming the “experiential inaccessibility” of that which is otherwise rendered “alien,” “abnormal,” and “deviant” in Silvers’ text.[[75]](#footnote-75) As Arendt states: “No opinion is self-evident. In matters of opinion, but not in matters of truth, our thinking is truly discursive, running, as it were, from place to place, from one part of the world to another, through all kinds of conflicting views, until it finally ascends from those particularities to some impartial generality.”[[76]](#footnote-76) In other words, imagination does *not* demand that one “know what actually goes on in the minds of others.” Indeed, by suggesting that one needs to “get” disability in order for it to be experientially accessible, Silvers comes dangerously close to endorsing the kind of “enormously enlarged empathy” that Arendt wants to avoid (*LKPP*, 43).

Notwithstanding Silvers’ critique, I believe that Arendt’s concept of representative thinking offers a possible approach for addressing those aspects of disability “which our categories our not equipped to understand.”[[77]](#footnote-77) In “Understanding and Politics,” Arendt speaks of imagination as a kind of understanding, without which “we would never be able to get our bearings in the world.”[[78]](#footnote-78) As she says, “True understanding does not tire of interminable dialogue and ‘vicious circles,’ because it trusts that imagination eventually will catch at least a glimpse of the always frightening light of truth.”[[79]](#footnote-79) Indeed, it is the effort entailed in representative thinking, the “testing that arises from contact with other people’s thinking” and the willingness to endure those “vicious circles” that has the most to offer disability studies (*LKPP,* 42). In approaching disability in this way, we might consider what Arendt referred to as thinking without those “categories and formulas that are deeply ingrained in our mind but whose basis of experience has long been forgotten and whose plausibility resides in their intellectual consistency rather than in their adequacy to actual events.”[[80]](#footnote-80) Rather than “resign ourselves to the preliminary understanding, which at once ranges the new among the old,” then, Arendt reminds us that this process is not simple and that we will occasionally, as Tom Shakespeare says, “lose the thread.”[[81]](#footnote-81)

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1. Shakespeare, “This Long Disease, My Life.” [↑](#footnote-ref-1)
2. Welch, “Disabled Climb Capital Steps to Plea for Government Protection.” [↑](#footnote-ref-2)
3. Eaton, “Disabled Persons Rally, Crawl up Capitol Steps.” From its inception in 1983 till 1990, ADAPT focused primarily on the accessibility of public transit. Following the passage of the ADA, it shifted its focus to personal attendant services, and has changed its name to “American Disabled for Attendant Programs Today” (the acronym remains the same). For more on ADAPT, see Fleischer and Zames, *The Disability Rights Movement: From Charity to Confrontation,* 82-85; and Pelka, *What We Have Done: An Oral History of the Disability Rights Movement*, 376-396 and 515-518. [↑](#footnote-ref-3)
4. Keelan, “Arrested at Age 7.” [↑](#footnote-ref-4)
5. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement,* 133. [↑](#footnote-ref-5)
6. Haller, “Crawling Toward Civil Rights: News Media Coverage of Disability Activism,” 89-90. Haller notes that “of the elite newspapers that covered the ‘crawl-in,’ the *Washington Post* wrote two articles on the Americans with Disabilities Act before March 1990; The *New York Times* had two articles, and the *Los Angeles Times* printed one op-ed piece that referred to the Act as ‘more loophole than law.’” According to Joel Shapiro, “the best way to describe the news coverage of the ADA was that there was very little of it” (Shapiro, “Disability Rights as Civil Rights: The Struggle for Recognition,” 59). [↑](#footnote-ref-6)
7. *Disability Rag,* “The Crawl-In,” 21. [↑](#footnote-ref-7)
8. Shapiro, *No Pity,* 133. [↑](#footnote-ref-8)
9. Harwood, “When Readers are Wrong.” [↑](#footnote-ref-9)
10. *Americans with Disabilities Act of 1990,* Public Law 101-336, 108th Cong., 2d sess. (July 26, 1990), §12101. [↑](#footnote-ref-10)
11. Jennings, quoted in Shapiro, *No Pity*, 130. [↑](#footnote-ref-11)
12. I borrow this concept of symmetry from Young’s “Asymmetrical Reciprocity: Moral Respect, Wonder, and Enlarged Thought.” Young is specifically referring to Seyla Benhabib’s understanding of “moral reciprocity as entailing that the perspective of self and other are reversible” (340). I will consider this article in more detail in the final section of this paper. [↑](#footnote-ref-12)
13. Shakespeare, “This Long Disease, My Life.” [↑](#footnote-ref-13)
14. Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability,* 11. [↑](#footnote-ref-14)
15. See, for example, Davis, “The End of Identity Politics and the Beginning of Dismodernism;” Garland-Thomson, *Staring: How We Look*; and McRuer, *Crip Theory: Cultural Signs of Queerness and Disability.* [↑](#footnote-ref-15)
16. Breckenridge and Vogler, “The Critical Limits of Embodiment: Disability’s Criticism,” 352. [↑](#footnote-ref-16)
17. Carlson, “Philosophers of Intellectual Disability,” 563. [↑](#footnote-ref-17)
18. Kochhar-Lindgren, “What Happens if You Put American Disability Studies at the Center?” 396. [↑](#footnote-ref-18)
19. Breckenridge and Vogler, “The Critical Limits of Embodiment,” 356. [↑](#footnote-ref-19)
20. Berlant, “Compassion (and Withholding),” 9. [↑](#footnote-ref-20)
21. While the ethical turn in political theory (and other fields) has received significant attention, (see, for example: Garber, Hanssen, and Walkowitz, *The Ethical Turn;* Honig, “Antigone’s Two Laws: Greek Tragedy and the Politics of Humanism;” Myers, *Worldly Ethics: Democratic Politics and Care for the World*), its appearance on the horizon of disability theory has gone relatively unremarked. With the exception of Margrit Shildrick’s work (*Dangerous Discourses of Disability, Subjectivity, and Sexuality*) few authors that I identify as part of this ethical turn use the term “ethics” to characterize their work. [↑](#footnote-ref-21)
22. Arendt, *On Revolution,* 63. Hereafter cited in text as *OR* with page references*.* [↑](#footnote-ref-22)
23. Arendt, *Lectures on Kant’s Political Philosophy,* 43. Hereafter cited in text as *LKPP* with page references. [↑](#footnote-ref-23)
24. Arendt, “Truth and Politics,” 237. [↑](#footnote-ref-24)
25. Silvers, “Reconciling Equality to Difference,” 36. [↑](#footnote-ref-25)
26. Arendt, “Understanding and Politics (The Difficulties of Understanding),” 323. [↑](#footnote-ref-26)
27. Ibid., 323. [↑](#footnote-ref-27)
28. Erickson, Lee, and von Schrader, “2010 Disability Status Report: United States,” 41. [↑](#footnote-ref-28)
29. McBryde Johnson, “The Disability Gulag.” [↑](#footnote-ref-29)
30. Hakim, “A Disabled Boy’s Death, and a System in Disarray.” [↑](#footnote-ref-30)
31. The staff member accused of killing Jonathan had, at the time of Jonathan’s death, worked more than 200 hours over the previous 15 days without a day off. According to Danny Hakim, who has investigated state-run institutions for the developmentally disabled in New York as part of an ongoing series (“Abused and Used”) for the *New York Times:* “State records show that of some 13,000 allegations of abuse in 2009 within state-operated and licensed homes, fewer than 5 percent were referred to law enforcement.” Of the 399 cases reviewed by the *Times,* “the state initiated termination proceedings in 129 of the cases reviewed but succeeded in just 30 of them...In the remainder of the cases, employees accused of abuse...either were suspended, were fined or had their vacation time reduced.” 25% of the employees involved were simply transferred to other facilities (Hakim, “At State-Run Homes, Abuse and Impunity”). [↑](#footnote-ref-31)
32. Prendergast, “And Now, a Necessarily Pathetic Response: A Response to Susan Schweik,” 240. [↑](#footnote-ref-32)
33. McRuer, *Crip Theory,* 30. [↑](#footnote-ref-33)
34. Schriempf, “(Re)fusing the Amputated Body: An Interactionist Bridge for Feminism and Disability,” 57. [↑](#footnote-ref-34)
35. “Feminist Disability Studies,” 1567. [↑](#footnote-ref-35)
36. Bumiller, “Quirky Citizens: Autism, Gender, and Reimagining Disability,” 983. [↑](#footnote-ref-36)
37. “Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation,” 141. [↑](#footnote-ref-37)
38. “The Disabled Body, Genealogy, and Undecidability,” 767. [↑](#footnote-ref-38)
39. Garland-Thomson, “Feminist Disability Studies,” 1557. [↑](#footnote-ref-39)
40. Garland-Thomson, “Shape Structures Story: Fresh and Feisty Stories about Disability,” 119. [↑](#footnote-ref-40)
41. See, for example: Davis, “The End of Identity Politics and the Beginning of Dismodernism;” Garland-Thomson, *Staring: How We Look*; McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*; Puar, “Coda: The Cost of Getting Better;” and Shildrick, *Dangerous Discourses of Disability, Subjectivity, and Sexuality.* [↑](#footnote-ref-41)
42. *Crip Theory,* 30. [↑](#footnote-ref-42)
43. Davis, “The End of Identity Politics and the Beginning of Dismodernism,” 241. [↑](#footnote-ref-43)
44. “Disability in Theory: From Social Constructionism to the New Realism of the Body,” 742. [↑](#footnote-ref-44)
45. *Ibid.,* 750. [↑](#footnote-ref-45)
46. Garland-Thomson quoted in McRuer, *Crip Theory,* 179. [↑](#footnote-ref-46)
47. “The Subject of True Feeling: Pain, Privacy, and Politics,” 51. [↑](#footnote-ref-47)
48. *Dangerous Discourses of Disability, Subjectivity, and Sexuality;* 175, 177. [↑](#footnote-ref-48)
49. Breckenridge and Vogler, “The Critical Limits of Embodiment,” 356. [↑](#footnote-ref-49)
50. Sandahl, “Queering the Crip or Cripping the Queer? Intersections of Queer and Crip Identities in Solo Autobiographical Performance,” 42. [↑](#footnote-ref-50)
51. Garland-Thomson, “Feminist Disability Studies,” 1568. [↑](#footnote-ref-51)
52. *Feminism and the Abyss of Freedom,* 22. [↑](#footnote-ref-52)
53. “Thinking and Moral Considerations: A Lecture,” 434. [↑](#footnote-ref-53)
54. Arendt, “On Humanity in Dark Times: Thoughts About Lessing.” [↑](#footnote-ref-54)
55. Silvers, 36. [↑](#footnote-ref-55)
56. “Rationing Medical Care: Rhetoric and Reality in the Oregon Health Plan,” 1583. [↑](#footnote-ref-56)
57. Egan, “Oregon Lists Illnesses by Priority to See Who Gets Medicaid Care.” According to lawmakers, where conditions ranked on the list to do with severity than with the frequency of the condition, cost of treatment, and estimated quality of life (which at least partially explains why the treatment of thumb-sucking would be ranked higher than the treatment of cystic fibrosis). [↑](#footnote-ref-57)
58. Young, “Asymmetrical Reciprocity,” 344. I tried to find more information on the survey and how it was conducted, as neither Young nor Silvers—who both discuss the Oregon Health Plan in detail—cite sources for this data. As a result, I am drawing mostly from their accounts of the survey and what can be gleaned from news accounts of the controversy. (see, for example, Egan, “Oregon Lists Illnesses by Priority to See who Gets Medicaid Care”). [↑](#footnote-ref-58)
59. Silvers, “Reconciling Equality to Difference,” 35. [↑](#footnote-ref-59)
60. Ibid., 35. [↑](#footnote-ref-60)
61. Clifford, “Making Disability Public in Deliberative Democracy,” 15. [↑](#footnote-ref-61)
62. Silvers, “Reconciling Equality to Difference,” 36. [↑](#footnote-ref-62)
63. Ibid., 36. [↑](#footnote-ref-63)
64. Ibid.; 33, 36. [↑](#footnote-ref-64)
65. Arendt, “Truth and Politics,” 237. [↑](#footnote-ref-65)
66. Silvers, “Reconciling Equality to Difference,” 36. [↑](#footnote-ref-66)
67. Young, “Asymmetrical Reciprocity,” 340. [↑](#footnote-ref-67)
68. Ibid., 349-50. While Young first says that “the idea of taking the standpoint of all others presumes the possibility of an identification between us all, that we can represent others to ourselves in the sense that we can be substitutable for one another,” she later seems to amend this assessment, suggesting that what is necessary for political judgment is both the ability to “take account of one another’s interests and perspectives,” but also to “consider the collective social processes and relationships that lie between us and which we have come to know together by discussing the world” (359, 360). [↑](#footnote-ref-68)
69. Arendt, “Understanding and Politics,” 323. [↑](#footnote-ref-69)
70. Kant, *Critique of Judgment,* §40, 161. [↑](#footnote-ref-70)
71. Arendt, “The Crisis in Culture,” 220. [↑](#footnote-ref-71)
72. Arendt, *LKPP*, 43. Quotes are from Kant’s *Critique of Judgment.*  [↑](#footnote-ref-72)
73. Silvers, “Reconciling Equality to Difference,” 36. [↑](#footnote-ref-73)
74. Arendt, “Understanding and Politics,” 323. [↑](#footnote-ref-74)
75. Silvers, “Reconciling Equality to Difference;” 35, 36. [↑](#footnote-ref-75)
76. Arendt, “Truth and Politics,” 238. [↑](#footnote-ref-76)
77. Arendt, “Understanding and Politics,” 313. [↑](#footnote-ref-77)
78. Ibid., 323. [↑](#footnote-ref-78)
79. Ibid., 322. [↑](#footnote-ref-79)
80. Arendt, quoted in Disch, *Hannah Arendt and the Limits of Philosophy,* 144. It is perhaps all the more fitting (or ironic) that Arendt also referred to this practice as “thinking without a banister” (143). [↑](#footnote-ref-80)
81. Arendt, “Understanding and Politics,” 313; Shakespeare, “This Long Disease, My Life.” [↑](#footnote-ref-81)