Is Intersectionality a Disabled Framework?

Presenting PWIVID: In/Visibility and Variability as Intracategorical Interventions

Cara Goldberg

Abstract

People with invisible and variable impairments and disabilities (or PWIVID) represent a significant subset of people with disabilities (PWD). This paper calls on those within the Critical Disability Studies (CDS) ‘silos’ and other disability fora to deploy the tradition of intracategorical intersectional analysis to address our internal “hierarchy, hegemony, and exclusivity” (Nash, 2008, p. 2) and “account for lived experience at neglected points of intersection” (McCall, 2005) regarding PWIVID. The PWIVID acronym – introduced in this paper as the counterpart to the seldom-acknowledged default PWD represented by those I term here PWOSID (people with obvious and stable impairments and disabilities) – helps highlight issues unequally represented in historical, political and theoretical accounts of disablement pertaining to non-apparent and unpredictable impairments – including disability identity and what Garland-Thomson (2014) calls “body management.” CDS and disability communities are invited to challenge the unexamined presumptions of McCall (2005) and other intersectional theorists that “mixed locations” are, on all bases, more akin to “dominant” (or “privileged”) ones than those seen as explicitly “subordinate” (or “burdened”) – at least when it comes to lived experiences of dis/ability – and to better recognise and reflect PWIVID’s unique voices and concerns.

Keywords

Invisible disabilities; variable disabilities; episodic disabilities; episodic conditions; intersectionality; chronic illness; intracategorical complexity.
L’intersectionnalité, est-elle une approche avantageuse pour l’analyse de l’incapacité?

Nous présentons le «PWIVID»: l’invisibilité et la variabilité comme interventions intra-catégoriques

Résumé


Mots clés

Déficiences invisibles; déficiences variables; déficiences épisodiques; conditions épisodiques; l’intersectionnalité; maladies chroniques; complexité intracatégorique.
Is Intersectionality A Disabled Framework?

Presenting PWIVID: In/Visibility and Variability as Intracategorical Interventions

As a response to the lengthy history of essentialism and exclusion that has plagued both feminist and anti-racist scholarship, the intersectional project centres the experiences of subjects whose voices have been ignored. (Jennifer Nash, 2008, p.3)

In recent decades, disability in the West has been “increasingly understood in terms of oppression and inequality” (Beauchamp-Pryor, 2011, p. 6). This paper\(^1\) calls on those within the Critical Disability Studies (CDS) ‘silo’ and other disability fora to draw upon the tradition of intersectional analysis to address our internal “hierarchy, hegemony, and exclusivity” (Nash, 2008, p. 2). In particular, I draw attention to those whom I categorise as ‘people with invisible and variable impairments and disabilities’ (PWIVID)\(^2\). PWIVID constitute a subset of ‘people with impairments and disabilities’ (PWID) – most often referred to simply as people with disabilities (PWD)\(^3\). Calling attention to experiences of impairment not equally represented in historical, political and theoretical accounts of disablement, I ask how CDS and disability ‘communities’ might move forward to recognise and reclaim the voices of PWIVID. Utilising my own observations\(^4\), along with

---

\(^1\) I am indebted to several reviewers (known and anonymous) for their comments on pre-publication versions of this paper, whose requests for clarification on key points – including my rationale for creating the PWIVID acronym – forced me to interrogate the reasons for some of my choices herein. This final version is much stronger for their questions and suggestions, for which I am grateful.

\(^2\) I opted to mobilise the terminology of “variable disabilities” as an alternative to the most analogous term in the literature (“episodic disabilities”) – which (as an anonymous reviewer observed) has a similar meaning, as well as a growing body of literature associated with it – in order to capture and emphasize, (as this same reviewer noted), that fluctuations in the presence and degree of non-stable impairments are often not a binary proposition, as the term “episodic” might imply.

\(^3\) For the sake of a common reference point for the general category of disabled people, I use the more customary PWD rather than PWID throughout this essay. However, given that impairment is a prerequisite of disability (e.g., see Souza, February 3, 2014) often overlooked within social-model-inspired disability circles, I see some utility in moving towards the adoption of PWID over PWD (not to mention its potential for monosyllabic pronouncement). That said, I am hesitant to move PWD in the LGBTQ+ direction of ever-expanding and increasingly specific initialisms – the latter of which have been clawed back with ‘umbrella’ terms (e.g., queer) and/or shorter short-forms (e.g., Diverse Sexuality and Gender (DSG) – see http://www.asexuality.org/en/topic/106135-a-new-acronym-dsg-vs-lgbtqia/).

\(^4\) As Mia Mingus (2010, February 25) notes, “If you have privilege, you can never be neutral, because you are constantly benefiting off of that privilege—*even at the same time as you are also being oppressed*. That is what “intersectionality” (for lack of a better word) is about.” Along these lines, my theorisation of and identification with the PWIVID concept coexist with and are informed by my (visible and invisible) experiences of both of privilege (e.g., my nationality, whiteness – as defined in my current context, access
those of other PWVID whose inclusion under the disability umbrella has been
problematised (e.g., see Souza, 2014, February 3), I aim to “account for lived
experience at neglected points of intersection” (McCall, 2005). I also challenge the
unexamined presumption of McCall and other intersectional theorists that “mixed
locations” are, on all bases, more akin to “dominant” (or “privileged”) ones than those
seen as explicitly “subordinate” (or “burdened”) – at least when it comes to lived
experiences of dis/ability. Piecing together a variety of sources, academic and popular, I
utilise my PWVID-specific “direct experience of the everyday world” as a “primary
ground” of knowledge in what Dorothy Smith has called an alternative approach (1974,
p. 11; 1990). Thus, I aim to highlight intracategorical issues in non-inclusive and non-
representative disability milieus and interrogate the common “assumption that [we're all]
‘on the same side’” (Morris, 1993, p. 56).

Re-'Re-Thinking Intersectionality'

_The problem with identity politics is not that it fails to transcend difference, as some
critics charge, but rather the opposite – that it frequently conflates or ignores intragroup
differences… [I]gnoring differences within groups contributes to tension among groups._
(Kimberlé Crenshaw, 1994)

In her critical article “Re-thinking Intersectionality,” Jennifer C. Nash (2008) asserts that:

Intersectionality, the notion that subjectivity is constituted by mutually
reinforcing vectors of race, gender, class, and sexuality, has emerged as the
primary theoretical tool designed to combat feminist hierarchy, hegemony,
and exclusivity[, becoming] the ‘gold standard’ multi-disciplinary approach for
analysing subjects’ experiences of both identity and oppression. (p. 2)

Nash attributes the emergence of the term intersectionality to late 1980s critical race
studies: “a scholarly movement born in the legal academy committed to problematizing
law’s purported colour-blindness, neutrality, and objectivity” (p. 13). She particularly
credits legal scholar Kimberlé Crenshaw’s seminal articulation of intersectionality as
having “galvanized an array of disciplines to consider questions of essentialism,

---

to education, etc.) and marginalization (e.g., my queerness, the intergenerational trauma related to and
direct effects of my being parented by a war-orphaned, international adoptee whose nuclear family was
murdered in an ethnic genocide, etc.).
exclusion, and complex identity in new ways.” But how does dis/ability fit into this problematic?

CDS could arguably be included amongst the array of “galvanized” disciplines to which Nash alludes in the quote above; however, her piece itself notably makes but a tokenistic mention of “able-bodiedness”\(^5\) (p. 10). Historically, then, it seems important to recall that the initial proliferation of ‘intersectional’ theories and methodologies happened partly as a critical response to (presumably well-intentioned) white feminists’ neglect of other feminists’ perspectives. As Brooks & Hesse-Biber (2007, p. 6) note, “the failure of academic scholarship and mainstream research to ‘give voice’ to women’s activities, experiences, and perspectives provoked early feminist scholars and researchers to seek remedies for these omissions.” In other words, it was those (specifically underrepresented racialised women) whose voices were not solicited or heard (adequately or often enough) who, upon being subjected to so many ostensibly inclusive narratives lacking standpoints resonant with their own, intervened with intersectional approaches.

In this light, Nash’s (p. 3) critique of feminism’s “perennial inattention to racial, ethnic, class, and sexual difference(s)” begs to be turned back upon itself – and towards us – to inspire some pointed questions:

- How might we, as disabled and disability-aware scholars, address the “perennial” tendency of some of the most intersectional anti-oppressive theories (and theorists) to routinely ignore disability in their substantive analyses?

---

\(^5\) This ‘tokenistic mention’ is a passing reference to Zack’s (2005, p. 7) allusion to “physical ableness” and “able-bodiedness” among possible categories of marginalisation and privilege that could be considered through an intersectional lens, as per: Zack, N. (2005) Inclusive Feminism: A Third Wave Theory of Women’s Commonality, Lanham, MD: Rowman & Littlefield Publishers, Inc.
• How far has intersectionality moved from its origins in critical race legal theory to truly being “the ‘gold standard’ multi-disciplinary approach for analysing subjects’ experiences of both identity and oppression”? Has ‘intersectional theory’ sufficiently extended beyond its initial “vectors of race, gender, class, and sexuality” (Nash, p. 2) to include other ‘multiply marginalised’ people (such as multiply marginalised PWD)?

• Has intersectionality, in practice, “become a useful tool for CDS [that] contribute[s] to in fact overcoming much of the marginalisation and discrimination of disabled people” (Meekosha & Shuttleworth, 2009, p. 62)? When the PWD category is included in intersectional analyses, and in CDS more generally, which PWD experiences are, by default, still excluded?

‘Cripping’ Intersectionality

*The body that causes… discomfort (by not fulfilling an expectation of whiteness) is the one who must work hard to make others comfortable. You have to pass by passing… by minimizing the signs of difference… [D]iversity work becomes willful work when we are willing to be the cause of disturbance. Perhaps we can only do this work, this work of agreeing to stand out and stand apart, this disturbing work, when we work with others.*

(Sara Ahmed, September 14, 2014)

Theoretically, a re-centring of dis/ability in ‘intersectional’ interdisciplinary conversations is more than just imaginable; as some (e.g., Piepmeier, Cantrell, & Maggio, 2014) have argued, it is already a project well under way. That said, one need not be too removed from intersectionality’s U.S-based critical race theory origins to notice the extent to which the specifically (presumably able-bodied) paradigmatic African American woman’s experiences constitute not only its epistemological foundation but also inform many subsequent developments and dialogues in the practice and rhetoric of intersectionality – and all for good historical and contextual reason. Still, those whose primary identities/oppressions are defined by less-theorised marginalised categorical
realms\(^6\) may need to keep working hard to make their voices heard and to expand the often self-referentially narrow focus of intersectionality towards more globally inclusive – or diversely particular – paradigms.

Further, mainstream disability scholarship and organising has itself frequently failed to account for non-paradigmatic (e.g., non-male, non-white, non-heterosexual, non-cis-gendered, and non-middle-or-upper-class) PWD; nor has it sufficiently acknowledged the sometimes antithetical interests of those relatively privileged PWD who, in setting the activist and scholarly agendas that purportedly represent all people with disabilities, have often thrown under the bus (so to speak) the ‘multiply marginalised’ on whose behalf intersectional methodologies were developed (e.g., see Ejiohu & Ware, 2008; Withers, 2012). Moreover, as disability philosopher Susan Wendell (1996) has pointed out, historically, the predictably-impaired, healthy disabled largely defined the priorities and goals of the disability movement. Disability theorists today echo these observations and continue to demand that efforts towards rights, consciousness, and scholarship incorporate frequently omitted elements such as variable/‘non-apparent’ impairments and more traditional ‘intersectional’ considerations (e.g., Orlando, 2012; Daley, Costa, & Ross, 2012).

Importing the notion of intersectionality ‘wholesale’ to disciplines like CDS as a framework for inclusivity, especially without a deeper historical and socio-cultural examination of the theory’s roots, has its drawbacks. Many marginalised groups (including people with different kinds of impairments) have used ableist rationales to secure their own rights and recognitions (see Withers); hence, the authenticity of some

\(^6\) For example: religion or nationality; shade or caste; unique/devalued embodiment, impairment, or health status; sub-cultural affiliation; and/or possibly even more individualised experiences of yet-un(der)politicised subjective experience.
groups’ merely adding ‘disability’ to the list of categories (i.e., race, class, gender, sex, etc.) deemed intersectionally important, without further questioning or acknowledging their underlying values and biases, may be suspect. Likewise, attempts to ‘push’ disability into broader intersectional frameworks must avoid reifying the sexism, racism, heterosexism, cissexism, and classism associated with disability mobilising in the past, as well as other internal divides between various PWD. As Jasbir Puar (2011) warns, “like the language of diversity, the language of intersectionality, its very invocation, it seems, largely substitutes for intersectional analysis itself.” Nonetheless, the methodological approaches and philosophical discourses grounding intersectional theories can, employed conscientiously, act as one possible starting place for those motivated to develop more comprehensive disability-inclusive theories and communities.

‘Intersecting’ Disability

For disability to emerge from embodiment, then, it must be recognized. Even when a disability is seldom discernible or legible—such as psychiatric conditions or many illnesses—the potential for its emergence, especially spontaneous occurrences or revelations, makes disability as well. Sometimes disability claims us through our appearance and sometimes it claims us through our functioning. Someone with a chronic illness may not meet the temporal demands the workplace expects. Someone with a psychiatric disability may not meet the sociability expectations of interpersonal networks. Someone who has seizures, autistic spectrum disability, chronic illness, psychiatric diagnosis, or is hard of hearing may not be recognizably disabled always or even often, but they become disabled when that characteristic emerges in some perceptible way in the social environment. (Rosemarie Garland-Thomson, 2014)

In the present moment, ‘intersectionality’ is often understood as an almost generic demand to take into account otherwise-unconsidered ‘complex’ overlapping
oppressions and identities. It can be invoked by anyone faced with a situation, pedagogical or practical, inadequately informed by some relevant multiply-marginalised perspective (e.g., assertions that certain remedies or laws would improve the lives of PWD, where in fact they would only benefit certain classes of PWD). The ‘intersectional intervention’ can be a well-considered response or ‘knee-jerk’ reaction (e.g., deploying the notion of intersectionality in classroom settings in efforts to call out what are perceived as under-qualified, over-essentialised claims). Puar (2011) cautions against language being invoked as a substitute for “intersectional analysis itself”; moreover, and despite not explicitly mentioning disability, her suggestion that “categories—race, gender, sexuality— are… events, actions, and encounters, between bodies, rather than simply entities and attributes of subjects” seems equally – even especially – applicable in the realm of dis/ability. Ideally, such an observation would remind us all to do our best to unpack and acknowledge our complicity in systems of oppression, even as we contemplate the actions and analyses we might undertake to challenge them.

In line with these possibilities, I hereby invite us to move the ‘intersectionality conversation’ beyond the “conventional mantra of race, gender, sexuality and class” critiqued by Meekosha and Shuttleworth (2009, p. 62) towards one particular site of ‘intracategorical’ (or, literally, ‘within-category’) ‘othering’: that of PWIVID – who, due to their impairments’ not being constant or immediately apparent, do not fit the

---

7 As an anonymous reviewer poignantly suggested, it is important to acknowledge here “the legacy of black feminist critical thought from which Kimberlé Crenshaw’s formulation of intersectionality arose (as well as some of the problems inherent in intersectionality’s cooption by white feminists as a depolitized means of managing complexity in research…”); For example, see Alexander-Floyd, 2012; Carbin & Edenheim, 2013; Erevelles & Minear, 2010; and Gines, 2011 – whose articles illustrate this point.

8 I use the word ‘invisible’ here for simplicity and recognisability (and because its “I” vowel makes my proposed initialisms pronounceable as an acronym). Later in this paper, I re-visit objections to the notion
paradigmatic PWD mould of ‘people with obvious and stable impairment and disabilities’ (PWOSID). In discussing impairments and disabilities themselves, I henceforth refer to IVID (‘invisible and variable impairments and disabilities’) and OSID (‘obvious and stable impairments and disabilities’).

The Categories Within: The Impairment-Disability Dichotomy

Even if one wholeheartedly accepts the purist ‘social model’ wet dream of a perfect binary separation of ‘impairment’ from ‘disability’ (which, again, I do not), there is no such thing as a purely constructed ‘disability’ without some underlying ‘impairment.’ And there is no ‘impairment’ without some degree of, at minimum, physical difficulty. (Valéria M. Souza, February 3, 2014)

According to Meekosha and Shuttleworth (p. 47), a discipline or field of study needs to “be aware of its own historicity and critically reflect on its conceptual framework” and “to engage in a dialogue with other cultures on the issues and concepts of current significance.” Along these lines, it has been noted that (Critical) Disability Studies has either failed to follow the lead of, or is lagging well behind, other interdisciplinary departments and movements (e.g., Feminist Studies; Trans/Gender Studies; Queer Studies; etc.) that have co-evolved as critical activist-scholar collaborations responding to their own marginalised constituencies (e.g., Souza, February 3, 2014). As an extension of (and garnering similar criticisms to) the mainstream disability activist movement, CDS has persisted for several decades in a ‘social model’ approach “premised on a binary split between ‘impairment’ (the underlying ‘physical specifics’ of

9 I introduce ‘PWOSID’ to problematise the notion that, by default, PWD are assumed to have obvious and stable disabilities unless otherwise specified (e.g., with a term like PWIVID), akin to ‘cisgender’ being an equally-weighted counterpart to trans* gender identities. Such terms call for further elaboration.
an individual’s embodiment) versus ‘disability’ (the socio-cultural, economic, and institutional oppression visited upon particular bodies as a result of prejudicial attitudes and beliefs regarding certain forms of embodiment)” – a binary “modeled after Feminism’s sex/gender binary” (Souza, 2014, February 3).

Valéria Souza goes so far as to accuse Disability Studies scholars and activists of perpetuating (internalised) ableism. In their privileging those with stable, physical impairments over those with other, more marginalised disabling conditions, such as impairments medically labelled as (chronic) illness, these paradigmatic PWD representatives suppress and silence the images and voices of the “unhealthy disabled,” thus “revealing the extent to which they themselves have internalized mainstream ideas about what constitutes ‘good,’ ‘correct,’ and ‘normal’ bodies” (Souza).

She goes on to propose that we treat impairment and disability (analogous to Butlerian sex and gender circa 1990) as “functionally synonymous and interchangeable terms” with neither being “understood as ‘purely physical’ nor ‘purely social’ (or cultural, or historical, etc.)” (Souza). In proposing to thus dissolve the “impairment/disability” dyad and the associated notion of “a pristine divide between ‘the biological’ and ‘the social,’” Souza clears a space for an impairment-inclusive disability category that she defines as “the situation produced when any individual exhibiting a ‘non-normative’ mode of embodiment enters into and interacts within a given social, cultural, linguistic, and historical context” (Souza).

Less radically critical voices (i.e., those willing to challenge but nonetheless work within the framework of an acknowledged impairment/disability distinction) have similarly insisted that the CDS pendulum must swing back from an outmoded anti-
impairment ‘social model’ approach to conceptualizing and politicising disability. Liz Crow’s demand that we “BRING BACK IMPAIRMENT!” in order to remove the prevalent taboos around discussing the unpleasant realities of impaired/disabled embodiment is now famous (1996 – caps in original). Similarly, Tom Shakespeare publicly recanted his earlier social model stance, boldly asserting “we cannot ignore the role of impairment and the body in our lives… A social constructionist approach that loses contact with the physical does us no favours” (2000, p. 162).

Shakespeare’s point that “reconciling the public and the private also means connecting the individual experience of the body, to the collective experience of social structures” (2000, p. 265) echoes the body-connected theorising that feminists, including disabled feminists (e.g., Morris, 1993; Wendell, 1989/1996; Erickson, 2007), have done for decades, and continue to do. For example, Kafer (2013, p. 7) highlights: “the social model with its impairment/disability distinction erases the lived realities of impairment; in its well-intentioned focus on the disabling effects of society, it overlooks the often-disabling effects of our bodies.”

Evidently, much work remains to be done before CDS can be recognised in this realm for fully employing “the critical self-reflexivity that is a hallmark of critical social theory” (Meekosha & Shuttleworth, p. 62) to a degree that justifies the “C” in its initialism: whether we opt to dismantle the impairment/disability binary or refocus our attention on its neglected left side.

---

10 The ‘social model’ is itself a ‘backlash’ against a vilified ‘medical model’ “according to which ‘disability’ (understood medically as synonymous with ‘impairment’) is portrayed as an individual problem that is both a.) undesirable and b.) needs to be ‘fixed’ or ‘cured’ through medical/institutional/scientific intervention” (Souza, 2014, February 3).

11 As Dr. Nancy Halifax refers to them: “the manymanymany women/feminists who never left bodytheorizing [sic]” (personal communication, November 24, 2014)
Intra-Categorical Intersectionality and PWD: Why bother distinguishing PWOSID from PWIVID?

*In the disability community, we speak as if some kinds of disability were visible, and others weren’t. Let me suggest a different approach: think about the ways different kinds of disability have become more familiar, and more visible, to you as you’ve gotten to know more disabled people.* (Cal Montgomery, 2001)

As noted above, the intersectionality framework has been applied for decades to the overlapping categories of race, gender, class, and sexuality, with disability, as a more recent addition, less fully incorporated into general intersectional awareness. In establishing PWIVID as a category of ‘marginalised intersectional identity’ that is, in itself, complex, I adopt a new approach to ‘intracategorical complexity’.12

According to Leslie McCall (2005), the “intracategorical complexity” approach to intersectionality “takes marginalized intersectional identities as an analytic starting point...in order to reveal the complexity of lived experience within such groups.” She attributes the development of this approach to “feminists of color” who “steered a middle course” in seeking to complicate group boundaries and use them in a more critical way, without totally rejecting “the social reality of categorization” (McCall). By contrast to “anticategorical” (in which “fixed categories [are] simplifying social fictions that produce inequalities in the process of producing differences”) and “intercategorical” (requiring a provisional adoption of “existing analytical categories to document relationships of inequality among social groups and changing configurations of inequality along multiple and conflicting dimensions”) approaches, a within-category, or intra-categorical,

---

12 Next logical steps would include investigating intersections between PWIVID and other categories of marginalisation (e.g., PWIVID who are female, transgender, racialised, working class or poor, multiply impaired/disabled, etc.); unfortunately, this analysis is outside the scope of the current paper.
approach is “critical of broad and sweeping acts of categorization” while complicating and using categories in a critical way (McCall, 2005).

Such an approach seems well-suited to an exploration of PWIVID. In addition to any non-disability-related marginalities they may inhabit, PWIVID are doubly burdened by: 1) living with the disabling effects of impairments/disabilities and 2) failing to have the nature and/or effects of their disabling impairments/disabilities recognised by others. Because PWIVID – including those labelled as having ‘chronic illnesses’ and other variably impairing conditions, as well as those whose embodied situations are not fully or adequately comprehended by either lay people or the medical system – are not as well-represented in scholarship and activism by and for PWD, their voices are less heard than those of PWOSID.

In her aptly-titled article “Invisible Disability,” N. Ann Davis (2005, p. 153) asserts that the examination of “the notion of invisible disability” is a worthwhile undertaking “in its own right.” She elaborates:

There are many individuals with conditions, illnesses, and structural or biomechanical anomalies that are life limiting but not readily discernible to others. People who suffer from severe depression, chronic pain, or posttraumatic stress disorder (PTSD); people who are violently allergic to common household chemicals; those who have a seizure disorder, chronic fatigue syndrome (CFS), or severe fibromyalgia; and those who have sustained a mild traumatic brain injury (MTBI) may all appear “normal” to people with whom they have casual interactions. Yet they may still be disabled: the quality of their lives may be no less profoundly or adversely impacted by these conditions than is the quality of life of those whose disabilities are more obvious... People whose disabilities are not generally perceived by others do not, for that reason alone, find it easier to minister to themselves or to engage productively and effectively in the world without having to endure pain, discomfort, and exhaustion. There is no reason to believe that the invisibility of a disability itself necessarily lessens its impact or makes the disability less serious. (Davis, 2005, pp. 153-154)
R. Janice Orlando’s (2012) thesis “Gimp Anthropology: Non-Apparent Disabilities and Navigating the Social” highlights the unique challenges faced by people with non-apparent, physical disabilities, as compared to those more visibly disabled. Describing how the “absence of visible cues indicating physical impairment… leav[es] the sufferer vulnerable to moral judgments and social sanctions when they are unable to embody and perform to cultural norms” and “generates a closeted status that the individual must learn to navigate,” Orlando goes so far as to assert that such individuals inhabit “a third space of functioning between the outwardly ‘healthy’ and the visibly disabled” (2012, p. ii). As such, the experiences of PWIVID are painted as qualitatively distinct, and thus meriting their own discussions and analyses to, as McCall (2005) might say, “account for lived experience at neglected points of intersection [that] reflect multiple subordinate locations as opposed to dominant or mixed locations.”

Issues of intracategorical nuance are often glossed over, even when the topic is broached. For example, Shildrick (2009, p. 82) writes of the necessity “to remind ourselves that disability takes many forms not all of which are written on the body,” elaborating that “it is all too easy to conflate what are variously called developmental or learning disabilities with physical disabilities, and although a similar analysis applied across categories may be productive, it may also obscure highly cogent differences.” Yet, in making a very valid point, Shildrick inadvertently reifies the notion that the degree to which one is physically impaired is ‘legible’ – to others – on one’s body; this assumption, no matter how erroneous, informs many PWIVID-specific experiences.

Some stigmas and other challenges faced by PWIVID in relation to PWOSiD are analogous to those faced by people who identify (or are identified) with the “B”
(bisexual) in the LGBTQ+ spectrum (Ford, 2015, March 14) or who are otherwise not ‘legible’ as ‘queer’ (e.g., VanNewkirk, 2008). For example, one may not be recognised for one’s actual embodied/phenomenological experiences (e.g., sexual/romantic orientation) due to visual and behavioural markers belying underlying ‘membership criteria.’ Such erasure, along with other invalidations of their lived realities, can be experienced by the ‘invisibly-different’ in the presence of ‘in-group’ and ‘out-group’ members alike (e.g., in both ‘queer’ and ‘straight’ company – see Yoshino (2000) on non-binary orientations; VanNewkirk (2008) on “femme lesbian” identities).

To illustrate how such intracategorical complexities can unfold across categories, consider the case of social events billed as queer women’s gatherings that explicitly exclude ‘heterosexual’ and ‘male-identified’ people. Such invitation parameters, set with the intention of fostering ‘queer women’s community,’ may speak to some of the female-oriented ‘flirtation and affiliation needs’ of all queer women attending these events. Nonetheless, they more comprehensively address the holistic needs of the ‘mono-sexual’ (or ‘lesbian’) attendees, who can invite their significant others and openly celebrate their relationships with (all of) them. Whereas, heterosexually-active bisexual/queer women may find themselves in the more socially awkward situation of 1) being prevented from having their male partners physically present and 2) feeling pressure to ‘closet’ or hide their heterosexual relationships, and thus obscure their full sexual-relational identities, due to pervasive ‘biphobia’ in such contexts (C.S., personal communication, 2014). Evidently, questions of visibility and variability of identities affect

---

groups other than PWD and raise similar questions of legitimacy and belonging in those realms.

Bringing the analogising back to a disability context, I call upon another politicised realm of sexuality: that of the (non-consensual) sexual objectification of women. It is undoubtedly true that many (able-bodied/presenting) women have experienced being overtly, non-consensually sexualised (and, relatedly, expected to reproduce) as oppressive; by contrast, many disabled women (with obvious disabilities) have fought against their equally non-consensual overt desexualisation (and, in some cases, involuntary sterilisation – a tragic history also shared with able-bodied racialized and poor white women\(^\text{14}\)). The latter’s still-ongoing struggles for simple recognition as agential sexual adult beings (e.g., see Finger, 1992; Erickson, 2007) have not generally been reflected by able-bodied feminists who, basing their politics on their personal experiences (e.g., of receiving more sexual attention, in more contexts, than they desired), purport to speak for ‘all women.’ Feminist discourses that condemn the presumably violating ‘gaze’ fail to address the experiences of (disabled) (also feminist) women who desire more, not less, sexual attention and recognition\(^\text{15}\). Similarly, as Anne Finger writes:

> Because the initial focus of the women’s movement was set by women who were overwhelmingly non-disabled (as well as young, white, and middle-class), the agenda of reproductive rights has tended to focus on the right to abortion as the central issue. Yet for disabled women, the right to bear and rear children is more at risk. (1992)

---


\(^{15}\) This section inspired, in part, by personal communication with Susan Wendell in 2014, reflecting on course material covered in her 1999 ‘Women and Disability’ class.
A shift in topical focus towards our universal needs – to receive adequate welcomed, consensual sexual attention, as well as reproductive education and choices, and also to be able to avoid unwanted attention, advances, and pregnancies – could help bridge this gap without alienating disabled feminists. Ultimately, violations on either side may be more triggering for different individuals, based on whether they have been more frequently subjected to unwanted advances or deprived of sexual attention and options, but at very least, the need for sexual validation and choice is shared by all people.

Similarly, non-inclusive and non-representative disability milieus and discourses that paint all PWD – PWOSID and PWIVID alike – with the same categorical brush, seeing PWOSID-specific issues as ‘all-PWD’ issues, are at risk of replicating and intensifying the invisibility and associated ‘closeted’ experiences of PWIVID in an ableist world. For example, most PWIVID have suffered through experiences (with strangers and intimates alike), in which they are expected to act as though they were perfectly able-bodied. If their appearances and/or disclosed diagnostic categories do not adequately justify their perceived ‘failures’ to perform, they may be judged as lazy, selfish, malingerers, drama queens, etc. (e.g., see McRuer & Mollow, 2012). Yet, it is far more common, both in CDS and in popular accounts representing ‘disabled perspectives,’ to hear about people who falsely assume that PWD with obvious markers of difference are incapable of acting or speaking on their own behalf. Meanwhile, few analogous discussions are publicly taken up by PWD regarding the effects on PWIVID of the common overestimations of their ‘abilities’ – or, as Eli Clare (1999, p. 67) might
put it, the degree to which PWVID are assumed to be “enabled” whether or not they actually are.

I recall here disabled feminist scholar Jenny Morris’ (1993, p. 56) expression of disappointment at how disability is “generally invisible in terms of feminism’s mainstream agenda.” She explains how she experienced this particular brand of ‘in-group insensitivity’ differently from her usual disenchantment at ableist encounters elsewhere – as betrayal, rather than ignorance or indifference – due to its shattering of any “assumption that [we’re] ‘on the same side’” (Morris, 1993, p. 56). As a CDS scholar (and human) with both ‘invisible’ and ‘variable’ impairments, I resonate with Morris’s observation. Her ‘insider’ sense of betrayal at the failure of mainstream feminism to speak to her personal experiences as a disabled woman recalls my own with CDS.

I eagerly anticipate the day that we claim a space in the institution “where we’re ready to acknowledge that we might be [or have said something] wrong” (Piepmeier, Cantrell, & Maggio, 2014) and work towards rectifying identified issues (i.e., through explicit incorporations of yet underrepresented topics and voices, and making appropriate amends). Only once we have acknowledged our differences, as well as our shared experiences and goals, can CDS and ‘disability communities’ truly purport to speak both critically and productively – with, and on behalf of, all PWD.

**The Questionable ‘Privilege’ of ‘Passing’: ‘Trace-ing’ the Invisible Double-Edge**

*I try to push boundaries… because I believe that this shaming silence… is why we don’t know how to respect one another’s bodies and one another’s boundaries. It is why we don’t know what consent can look like… [T]he more and more we talk about that which we have such a hard time talking about, then we will all feel a little less ashamed and we will all be a little more open to new possibilities and new kinds of pleasure… And beauty will become something more than being able-bodied, young and white. And sexual autonomy and expression will be something that we will all have the right to. And consent will evolve into something that we will all be versed in practicing. It is on*
account of these hopes that I talk about sex all of the time. Loudly. On principle. (Kaleigh Trace, 2014, pp. 6-7)

In *Hot, Wet, and Shaking: How I Learned to Talk About Sex*, self-identified queer disabled author and sex educator Kaleigh Trace (2014) writes:

“Disabled” is such a broad identifier, and having a disability can look so many different ways. If you see me sitting or in photographs you would not necessarily know it. Until you see me walk, you would probably not guess it. All of this means that I pass. I am sometimes assumed to be nondisabled. Riding my trike makes me more visibly disabled. When I am on my trike, I get the most commentary. When I am on “training wheels,” people take full liberty to yell at me, tease me, and ask me what’s wrong with me. When I let those comments go, left unnoticed, I am allowing them to proliferate. People with different disabilities than mine may experience this kind of verbal harassment more regularly than I do. And so because of my relative position of privilege, I want to make sure I am always using my voice. Having a voice is a right that so many of us are systemically denied access to. I want to make sure I use mine when I can. (pp. 65-66)

Trace’s spinal cord injury – the result of a childhood car crash – led to her current “wobbly two-step [that] gets [her] to all of the places that [she] need[s] to go” (p. 3).

Visibility, with regard to both disability and sexuality, is a dominant theme running – or, perhaps, two-stepping – through Trace’s mostly autobiographical narrative. One way to frame being read incorrectly as both able-bodied and heterosexual, as Trace notes, is as “privilege” (p. 66): insofar as such ‘passing’ enables avoidance of the stigma and abuse that result when non-normative embodiments or orientations are readily visible/legible to others.

Trace takes up of the ‘privilege of passing’ within an anti-oppressive framework that calls upon her “to make sure [she is] always using [her] voice” because “[h]aving a

---

16 In Trace’s own words (2014, p. 127): “The version of me that I have written here is not all true. I am a shameless exaggerator, always have been. Here I wrote someone whom I sometimes am and whom I hope to be more often. I wrote a version of me who is not afraid to be unapologetically earnest. I wrote a version of me who throws herself into vulnerability with seeming abandon. I wrote a version of me who fucks and fights and loves. I wrote this version of me because to do so matters – sex-positive narratives of disability are needed.”
voice is a right that so many of us are systemically denied access to” (p. 66). Within such a framework, both ‘privilege’ and ‘passing’ are almost dirty words; tinged with a sense of ‘traitorship’ at unmerited access to social, financial, educational, health, or sexual opportunities due to factors based upon which one is situated – or is perceived as being situated – higher than others within an imagined socio-cultural/economic pyramid.

However, I suggest here that there is a seldom-acknowledged ‘shadow side’ to what some might refer to as the ‘privilege of passing as able-bodied’; it begins with denial and erasure alluded to above, based upon which PWIVID might empathise with the experiences of people with non-mono-sexual orientations and identities (e.g., see Yoshino, 2000). For example, despite sometimes being mistaken as being able-bodied, Trace otherwise writes self-assuredly about her embodied experience as a PWOSID whose disability ‘status’ would be difficult for anyone to challenge:

Having this beautiful, disabled body and living in this world with such an obvious difference has shaped me irrevocably. Being disabled informs every single experience I have with every person, every street corner, every building and every set of stairs. I am, and have always been, constantly reminded that my body is different from “normal” bodies, that it is actually physically impossible for me to conform to hegemonic standards of being.

(2014, p. 3)

In contrast to PWOSID – whose “obvious difference,” as Trace phrases it, calls attention to their impairments/disabilities – many PWIVID are not “constantly reminded” by others that their bodies are different from “normal” bodies; for them, such reminders of their IVID, and the challenges they pose, come most frequently from within (with others either ignoring or doubting their nature and/or existence). Granted, except in situations where their impairments cause them to act in socially unacceptable ways that
elicit negative responses, PWIVID often benefit – to whatever degree that the absence of bullying or abuse can be seen as a benefit – from how strangers do not often take “full liberty to yell at” them, tease them, or ask them what’s wrong with them on the street, as Trace describes happening to her whenever she rides her bike with “training wheels” (p. 65).

However, a lack of ‘superficial’ ableist stigma (and evasion of the accompanying verbal harassment and other forms of bullying and exclusionary practices that it brings) can go hand in hand with a lack of deeper recognition from otherwise-compassionate people. It is also, indeed, “actually physically impossible” for PWIVID “to conform to hegemonic standards of being” (Trace, 2014, p. 3); yet this fact is seldom externally validated or accommodated without considerable explanation on the part of PWIVID themselves (and/or their intimate allies). PWIVID’s experience of being disabled may still inform their every experience “with every person, every street corner, every building and every set of stairs” (Trace, p. 3) – but in such a way that the effects of their impairments are less frequently ‘seen’ by others and therefore more frequently challenged or ignored from a place of blanket denial of their equally real – if less obvious – differences.

The empirical method upon which modern medicine and related sciences are (in theory) based requires, on the most basic level, visual (or otherwise “objectively testable”) validation. Much to the detriment of PWIVID, if their embodied situation can’t be seen with the naked eye (especially in the absence of a medical authority’s offering a translatable, justification-worthy narrative), it is sometimes assumed not to ‘really’ exist. In terms of how this authority shapes what we ‘see,’ Susan Wendell has elaborated:
Some of the consequences of the cognitive and social authority of scientific Western medicine to describe our bodies in the societies where it holds sway… affects how we experience our bodies, contributing its objectifying perspective to the alienation already fostered by other aspects of commercial cultures. It affects how a society describes our experiences and validates or invalidates them, adding the burden of epistemic invalidation to many people’s experiences of illness and disability. It also affects how a society supports or fails to support our bodily suffering and struggles, for people who are ill or disabled without a medical diagnosis are not eligible for social programmes and are frequently abandoned by friends and family. (1996, p. 9)

In this respect, it might be argued that – in some cases – by virtue of the very ‘obviousness’ of their impaired/disabled states, PWOSID are at an advantage, or in a relatively ‘privileged’ position, compared to those with IVID; specifically in contexts where others’ recognition of one’s impairment/disability status can confer benefits (social, financial, medical, or otherwise). In other words, while OSID’s unambiguous markers of ‘actual differences’ can bring about deleterious consequences, they also give credence to PWOSID’s phenomenological experiences and biological realities: a credence often withheld from PWIVID for their lack of such obvious and stable markers, without which the consequences can also be (if differently) dire.

Does Your IVID Make You Livid? The Importance of Recognising (Invisible) Experiences of Impairment

Sometimes we may feel, and be, very disabled; sometimes quite the opposite… If I’m having a ‘good’ day, or if my problems are invisible, then people with a very visible disability or a benefits assessment officer may think I’m a fraud if I claim to be a disabled person. However, on a ‘bad’ day I’d be disbelieved if I claimed to be anything but! …Would that we were all regarded as being in one camp, a camp of human beings, but back to reality… [L]et us… educate society into understanding that there are such things as ‘invisible disability’, ‘partial disability’, ‘intermittent disability’, ‘variable disability’, ‘fluctuating disability’. (Jill Holroyd, 2009)

According to the Invisible Disabilities Association, ‘invisible’ (or, alternately, non-apparent or hidden or unrecognised) disabilities encompass “mild to severe debilitating
conditions” that can include “fatigue, cognitive dysfunctions, mental disorders or pain” (IDA, 2014). ‘Variable’ (or partial or intermittent or fluctuating – see Holroyd, 2009) impairments can range along the axis from ‘obvious’ to ‘non-apparent’; these are characterised by their instability and their ‘symptoms’ may vary (or fluctuate) in presence, intensity, and/or severity over time. Within the traditional ‘impairment-disability’ binary\(^{17}\), it is relevant to note a) that not all impairments are always disabling and b) that both impairments and disabilities can be distinctly apparent or recognised; stable or intermittent; static or variable/fluctuating.

Some experiences of embodiment and dis/ability are almost inherently ‘invisible’ in that they take considerable effort to be ‘seen’ by, or made legible to, most other people, most of the time (e.g., the ‘work’ done by people with allergies and chemical sensitivities to avoid, if they are successful in doing so, a reaction; the less obvious life-altering effects of the conditions diagnosed as Crohn’s or IBS, ME or Chronic Fatigue Syndrome, fibromyalgia, Marfan’s, Ehlers Danlos Syndrome; etc.). Others are rendered ‘invisible’ only through considerable individual effort (e.g., a practiced smile to cover a pain-induced wince; a summoning of adrenaline reserves to get through a work day ‘normally’ rather than let oneself rest or collapse in fatigue; etc.) and social engineering (e.g., overt policies and less tangible social mores that discourage discussions and/or other revelations of one’s failures to live up to embodied ideals – resulting, for example, in people calling in sick rather than showing up for work at less-than-optimal productivity levels). In essence, we are generally expected at least to downplay, if not hide, any evidence of ‘symptoms’; by design, norm structures keep lived experiences of

\(^{17}\) Although, as noted above, this binary is conceptually contestable and has been dismissed by some (e.g., Souza, February 3, 2014) as an artificially dichotomous ‘common sense’ framework, I draw on it here as a shared semantic reference point.
'abnormal' embodiments out of the 'common' consciousness.

Although all PWD are prone to being blamed for their unfortunate fate or karma, as noted above, those whose impairments are least easily recognised and assimilated into common understandings of 'disability' categorisation are susceptible to a particular brand of exclusionary judgment. “The habit most of us have of blaming the victim, by wondering or overtly asking ‘Are you really doing enough to change your situation?’” is widespread (Kaufman, Silverberg, & Odette, 2003, pp. 6-7). PWIVID are often themselves relegated to – or forced to hide their struggles within – the ‘private sphere’ (Wendell, 1996, p. 40) or ‘closet’ (Samuels, 2003). While PWOSID may be subject to similar pressures, those who are able to ‘come out’ – and are supported in doing so – can make access demands based on the visible stability of their OSID not as easily granted those with IVID. Instead of being invited into a sense of solidarity with other PWD, PWIVID – who alternately ‘pass’ or ‘are passed’ as non-disabled – inhabit an especially vulnerable realm of non-belonging.

Outsiders amongst both the able-bodied and the proud PWOSID, PWIVID may feel inferior to the former (e.g., when the productivity by which they are comparatively judged is limited by their IVID) and yet insufficiently entitled to make the same kinds of claims for support as the latter (due to internalised notions that ‘real’ disability looks like OSID). Regardless, they cannot help but be at the mercy of what Kafer (2013, p. 7) calls “the often-disabling effects of our bodies.” When impairments and related struggles go unrecognised, “[s]hame and guilt can arise at any time. Shame for being a social pariah, 

\footnote{18 It is in the context of racialisation and sexual orientation, rather than disability, that Ralina Joseph (2012, p. 59) explicitly makes use of the phrase “passing versus being passed.” Similarly, Rachel Gorman – without using the exact term ‘being passed’ – discusses (p. 5) and politicises (p. 8) Sara Ahmed’s notion of ‘passing’ in her 2011 article “Obama’s my dad’: Mixed race suspects, political anxiety and the new imperialism.”}
and guilt that a loved one has to defend you to others because of it” (Orlando, 2012, p. 63) – or simply for not living up to one’s own and others’ unachievable expectations. In addition, “denial of their experience is a major source of loneliness, alienation, and despair in people with unrecognized disabilities” (Jeffreys, 1982, paraphrased in Wendell, p. 25).

(In)Conclusions: Why didn’t the invisibly disabled chickens cross the road? (They got stuck in the intersection.)

My reflections as a disabled/non-disabled activist/researcher helped in my realisation that to be an ‘insider’, to ‘fit in’, extends beyond any fixed category and is about the shared experience of oppression. (Karen Beauchamp-Pryor, 2011, p. 15)

In their recent exploration of sex worker empowerment and solidarity, Avenatti and Jones (2015, p. 91) concluded, in reference to an article by Schwartz, Meisenhelder, Ma, and Reed (2003), that “individuals who engage in political organising around their identity group report higher levels of happiness, pride, and greater feelings of safety.” Yet the road to empowerment and solidarity for PWD of all stripes is littered with many obstacles and barriers (e.g., see Beauchamp-Pryor’s 2011 examination of the politics around individual’s choices to pursue “cures” for their impairing conditions). Offering another viewpoint, Francisco Ortega (2009, p. 427) has commented that “the search for new and non-pathologized forms of identity and community stands in tension with reductionistic identity politics.” In his discussion of autistic identity, he critiques the “aggressive identity politics advanced by the radical activists of the autistic movement, who appropriate the right to speak in the name of every person diagnosed with autism” and “obliterate difference within the autistic movement.”

Even as I challenge the homogeneous hegemonic PWOSID-centric image of
those depicted as ‘rightfully belonging’ in the PWD category, I feel concerned by the myriad interests and conflicts of interest at play. I do not wish to similarly subsume all PWIVID into yet another category that merely re-effaces the still-complex ‘intracategorical heterogeneity’ within it; nor do I want to advocate a scenario under which some speak on behalf of others whose stances and/or best interests they do not truly represent.

As noted throughout this paper, certain kinds of impairments/disabilities – namely, those that are visible or obvious (versus invisible or non-apparent) and stable/predictably progressive or constant (versus variable or intermittent) – are more easily taken into account by others; such recognition is an important factor informing whether one’s body (or self) is legible\(^\text{19}\) as impaired/disabled. Yet, engaging in conversations that name the relevant issues becomes difficult for a number of reasons, including that, on a socio-linguistic level, the very concept of ‘invisible disability’ is identified as problematic\(^\text{20}\) by some (e.g., Montgomery, 2001; Orlando, 2012) and embraced by others (e.g., Davis, 2005). Indeed, the word ‘invisible’ may remove some onus from a ‘perceiver’ to notice disability, linguistically rendering ‘invisibility’ an inherent attribute of a disability (and/or impairment) itself; yet, ‘invisibility’ is, in its most literal sense, a direct reflection of many people’s lived experiences of IVID (their own and others’). That the term ‘invisible’ makes ‘looking’ the dominant mode of taking in information may, semantically, erase other equally valid kinds of non-sight-based

\(^{19}\) Here, I borrow from Ralina Joseph’s (2012, p. 60) usage of “the visible versus invisible or legible versus illegible” in the context of racialisation and sexual orientation, rather than disability – highlighting the easy, if sometimes imperfectly analogous, transferability of concepts between disciplines.

\(^{20}\) E.g., see Janice Orlando’s (2012) preface for a primer on some issues leading to her choice of the term ‘non-apparent’ and Cal Montgomery’s (2001) insistence that “a distinction between visible and invisible disability is [neither] useful [n]or even meaningful.”
knowing (e.g., the perceptions of people with visual impairments). Nonetheless, few 
would contest that PWD’s experiences differ depending on the degree to which those 
around them notice, and are appropriately responsive to and supportive of, their 
impairments/disabilities and related needs; and sight is, every-increasingly, the 
dominant mode through which most people make at least initial appraisals of embodied 
situations and capacities. Evidently, further research, writing, and dialogue will be 
required in order in order to untangle how comprehensions of PWIVID might be taken 
up within discourses informed by ‘intracategorical’ intersectionality, as well as other 
thetical and methodological frameworks.

As a relatively new interdisciplinary academic field, CDS now has the opportunity 
– and, arguably, the responsibility – to remedy its historic lapses. Will we take the lead 
from other anti-oppressive movements and disciplines that have been accused of 
perpetuating oppressions internally and responded accordingly\textsuperscript{21}? Can we work 
together to rectify the biases and omissions that we, as researchers, teachers, and 
advocates, have been propagating (and/or be honest about our past and current 
weaknesses in these realms)? In other words, can CDS – which inevitably absorbs at 
least some of the ableist biases of a ‘dominant culture’ hostile to the challenges of living 
with all impairments/disabilities, including IVID – “be institutionalized, recognize 
ourselves and be recognized as a discipline, and still be agents of social change” 
(Piepmeier, Cantrell, & Maggio, 2014)?

\textsuperscript{21} E.g., Women’s and Gender Studies programs (and feminist discourses) have, over time, acknowledged 
and responded to legitimate accusations of their own embedded racism, classism, ableism, and 
transphobia by altering previous stances and practices to better reflect and accommodate the needs and 
perspectives of marginalised constituencies, consciously incorporating them into their core teachings.
In asking these questions, I am aware of my standpoint as a PWIVID; I cannot deny my vested interest, nor offer any pretense of capacity to distinguish objectively between advocacy and self-advocacy. Many within the CDS field, routinely acknowledge and discuss the kinds of impairments and disabilities that might be classified as IVIED; and yet, as far as I am aware, there exist no courses that explicitly prioritise PWIVID-centric topics and related subject matter. For now, I hope that by identifying and interrogating these topics, we can begin some important conversations that bring us closer together; and towards the places and spaces where, in the words of Kaleigh Trace (p. 7), “we will all feel a little less ashamed and we will all be a little more open to new possibilities.”

References


---

22 E.g., unpacking how IVIED, and the ‘passing’ – chosen or not – that PWIVID do, can only be read unqualifiedly as ‘privilege’ if a scenario constitutes chosen privacy, as opposed to involuntary ‘closeting’ and its accompanying negative repercussions.

23 E.g., examining the difficulties faced by those wishing to address impairment/disability issues relegated to the hidden side of the private-public divide.
Disability and Society, 26.1.


friendly handbook for young and youngish adults with a rheumatic disorder.


http://valeriamsouza.wordpress.com/2014/02/03/whos-afraid-of-chronic-illness-as-disability-an-entire-field-apparently/


