

## **Taking Tragic Measures? Disability Studies' Anti-Metrology and the Government of Thalidomide**

### **Abstract**

*This paper interrogates the relationship between thalidomiders, the name used by victims of the drug thalidomide, and the kinds of subjectivity assumed in disability studies as an activist research enterprise. The thalidomide case presents a fundamental challenge to disability studies' understanding of tragedy. I begin by reviewing some founding and more recent literature in disability studies. Next, I discuss the thalidomide tragedy, and how victims groups are using their existence as tragic in order to participate in the drug's regulation and the public narratives of the drug. In the third section of this paper, I discuss three perspectives on subject formation, the Foucauldian, the Heideggerian, and Actor-Network Theory, and ask how we can make sense of this instance tragic subject-formation. I make a distinction between 'active' and 'passive' tragedy discourse, and conclude with a discussion of how disability studies might continue to talk about active tragedy.*

KEYWORDS: Subjectivity; Heidegger; Foucault; Actor-Network Theory; Disability Studies; Thalidomiders

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### **Introduction**

Disability Studies has been (anti)metrological since its origin as an academic discipline, seeking to shift analytical emphasis from 'problem' bodies to problem time-spaces that exclude them.<sup>1</sup> Part of this shift involves departure from the so-called 'personal tragedy' view of disability, first discussed in Michael Oliver's *The Politics of Disablement* (1990), where this exclusion is causally related to biological pathology rather than exclusionary social organization. While disability scholars like Michael Oliver seek to get tragedy off the academic and policy agenda, Thalidomiders – those born with congenital birth defects resulting from prenatal ingestion of the drug thalidomide – are doing exactly the opposite. They are explicitly *claiming* victim status in order to participate in the global governance of thalidomide, which has re-emerged as a drug to treat a host of conditions, leprosy and cancer included. They are not claiming victimhood, however, singly in terms of past medical tragedy. They point to material neglect from governments worldwide, as well as Chemie Grünenthal, the (West) German company that first synthesized the compound, and later, distributed it worldwide. In this paper, I seek to examine the thalidomider's victim-status through three perspectives on subject formation, namely, the Foucauldian, Heideggerian and Actor-Network approaches. Though they vary in many ways, they agree on (at least) one point:

subjectivity is both actively built and historically situated. In this case, thalidomiders assemble themselves *as victims* so that they may participate in the government of others. I suggest that the politics of victimhood does indeed have a place on the disability studies agenda, though actively and in terms of what philosopher Annemarie Mol calls ‘ontological politics’, than as complacency, exclusion and defeat. I conclude with some remarks on anti-metrological discourse and practice within disability studies and without.

### **Disability studies and anti-metrology**

Various strands of anti-metrology have been developed within disability studies. Perhaps (anti)metrology is apt: disability studies, plural, have sought to de-center *particular* forms of measurement, and replace them with those that recognize and respect the existence of disabled persons. Two are particularly prominent: those of Michael Oliver and Tanya Titchkosky. Though these perspectives differ in many respects, they share common ground in emphasizing the social and material situations to which disabled persons are subjected, and exposing the recurrent and repressive narrative of inevitable personal tragedy against which disabled lives are read.

Michael Oliver’s *The Politics of Disablement* (1990) is the most representative work of the so-called ‘British Social Model’ of disability. The social model is built on a radical divide between disability and impairment. ‘Impairments’ are biological maladies affecting persons. ‘Disability’, on the other hand, is the state of being excluded by lacking accommodation for those conditions. This means a radical divide between pathology and oppression. Disability research is emancipatory research: disabled persons should pursue it, and aim to remove social and physical barriers that oppress them.<sup>2</sup> Oliver argues that the ‘ideology of individualism’ or ‘personal tragedy view of disability’ manifests when the exclusion of disabled people is causally related to their impairments. The primary mechanism of measuring disability this way is the medical model, to which the social model is directly opposed.<sup>3</sup> Oliver’s work can be said to be anti-metrological on two counts: he is critical of measuring practices insensitive to the barriers that produce disability in the first place, and secondly opposed to the use of ‘tragedy’ as a measure against which disability is read.

There are many criticisms that have been leveled against Oliver’s work and the social model more generally. First, there are objections about the tenability of the radical divide between impairment and disability, between the natural and the social (see Hughes & Paterson, 1997; Schillmeier, 2007). Where, exactly, should we draw the line between the two? Why can’t the sociology of impairment proceed? Secondly, others have questioned the extent to which social model is able to accurately reflect the experience of *all* disabled persons (Shakespeare, 2006). The Union of the Physically Impaired Against Segregation, whose *Fundamental Principles* (1975) inspired Oliver’s ontological divide, was primarily white, male and wheelchair based. While Oliver’s work might be anti-metrological in one sense, this ideal type disabled person is the measure for most of his research. Despite these objections, however, the opposition to both personal tragedy and displacing strictly medical understandings of disability have become founding themes in disability studies as an autonomous academic discipline.

More recent ‘anti-metrology’ is found in Titchkosky’s *Reading and Writing Disability Differently* (2007), where she engages key Canadian policy documents on the government of disability. While Oliver’s project stemmed from a historical materialist standpoint, Titchkosky borrows from Dorothy Smith, Donna Haraway and Michel Foucault (among others) to trace the

manner through which disability is defined first as problem and secondarily as a problem as distinct from those encountered by 'normate' Canadians.<sup>4</sup> Here disability is not simply measured, but it is generally enacted *as difference* and as a problem *to be solved* in governing texts.

To design a disability verification tax credit form; to report a story; to write an account, case or file; to develop a policy on embodied differences: these practices enact the meaning of disability through text. In cultures that assume literacy as a normative value, text becomes a method and a location for the organization, reproduction, and, thereby, enactment, of disability's meanings (Titchkosky, 2007, p. 28).<sup>5</sup>

Titchkosky concludes the first chapter of *Reading* with a clear outline of her interdisciplinary disability studies perspective and, aptly, its relation to measure. It also serves to display her similarities and differences to Oliver's British social model perspective.

A disability studies perspective is one that rejects the idea that disability can be studied as an object in and of itself. [...] Wherever] and however disability appears, it appears in the midst of other people.

Disability is, therefore, a social and political phenomenon and should be studied as such. Disability does not appear outside of our social, historical and political relations. [...] Attending to disability as a meaningful concept built from, and enunciated within, daily life leads to a form of social inquiry that take disability into account by examining the interrelation between conceptions of disabled and non-disabled people (Titchkosky, 2007, pp. 37-38).

While Titchkosky sees disability as 'social' because it is an emergent property of interpersonal action, textual or face-to-face, Oliver sees disability as social because societies exclude disabled persons. For Oliver, medicine is off the emancipatory agenda because, by definition, disability has – or *should have* – nothing to do with it. To see disability singly as medical malfunction is to commit a politically reactionary 'category mistake' (Ryle, 1949): medical problems and social oppression exist in different categories of things, though ideology disguises arbitrary exclusion as medical tragedy.<sup>6</sup> It is our job, both as activists and scholars, to sort them out. In contrast, Titchkosky seeks to make evident the techniques that reduce disability to a singly medical and individual matter. Haraway (1994) names one such technique the 'god trick': the textual obfuscation of the partial perspective underlying the production of documents claiming to engage disability objectively. Whereas Oliver appeals to the efficacy of capitalist ideology, Titchkosky seeks to recreate the socio-material environment where 'official text producers' make disability meaningful. The medical enterprise is prominent in this regard, but it is not the sole proprietor.

The similarity of the twin sociologies presented above outweighs their differences: the primary barrier faced by disabled persons is not tragedy, understood in terms of insufficient corporeal existence. Tragedy is not a natural or pre-existing state of affairs. The real tragedy faced by disabled persons is, instead, environmentally contingent exclusion located within the interaction order.<sup>7</sup> This ordering occurs at various sites at various scales, in the face-to-face encounter, through the channels of bureaucracy, in doctor-patient dialogue,<sup>8</sup> in white papers and government forms. Seeing disability only as tragedy fails to see its extra-biological elements and glosses over the times and spaces in which disabling processes occur. Academic research has, at times past and

present, contributed to the causal misattribution of this tragedy to biological malady. Both Oliver and Titchkosky argue that academic research can and must make evident disability's socio-material contingency, while studying a more humane way forward. In all of these ways disability studies has to do with 'measure' and 'tragedy', with tragedy as a measure of existence, as a norm to be combated, and the reorganization of academic dialogue in the service of that fight.

### **Thalidomide**

So, in the disability studies outlined above, tragedy has no place in the measure of disability. Or, restated, the tragedy lies not in problem bodies but rather in their mismanagement, either in terms of socio-material barriers or their textual disguise. If this is admitted, how might we account for disabled persons who present themselves as victims of a tragedy? Do they count as part of the disabled persons' movement and for its emancipatory agenda? Here I want to address the thalidomide 'tragedy'. I use that word specifically because 'victims' groups use it worldwide (again, 'victims' is their word choice). The Canadian victims of the thalidomide tragedy call themselves 'thalidomiders'. I'll first outline the events in general, and then move to two specific moments to substantiate this paper's reflexive reconsideration of disability studies and victimhood.

In order to demonstrate how thalidomiders have engaged in the politics of victimhood, some historical background is required. Thalidomide (in Germany: *Contergan*; United Kingdom and Canada: *Distival*) was first synthesized by Chemie Grünenthal in 1954, and became a popular sedative, sold under 51 brand names in 46 countries (Timmermans & Leiter, 2000, p. 44). The compound was prescribed primarily to treat morning sickness, but proved teratogenic (Franks et al., 2004). The drug caused numerous fetal malformations,<sup>9</sup> most notoriously phocomelia, "congenital deformity in which the hands or feet are attached closely to the trunk, the limbs being grossly underdeveloped or absent." (OED) Australian William McBride and German Widukind Lens independently noted these properties, and the drug was eventually removed from pharmacy shelves worldwide by the end of 1962, due to association with these effects (McBride, 2004). An estimated 10000 children were affected worldwide, forty percent of them in Germany (estimates vary due to terminated pregnancies, Daemmrich, 2002, p. 138). Since 1962, thalidomide has returned numerous times to market, as a treatment for leprosy, multiple myeloma, a form of cancer, AIDS wasting syndrome, and experimentally for a host of other conditions (see 'indications' in Prommer et al., 2011).

I want to focus on two specific events in thalidomide history. The first is the Thalidomide Victims Association of Canada's (TVAC) testimony at the September 1997 FDA and, a week later, NIH meetings regarding Celgene Corporation's application to produce thalidomide in the USA, under the auspices of the 1983 Orphan Drug Act.<sup>10</sup> Second is the reaction from thalidomiders worldwide to the recently unveiled thalidomide memorial, at Grünenthal's headquarters in Stolberg, Germany on 31<sup>st</sup> August 2012. The monument, "The Sick Child", was accompanied by a statement by the Grünenthal's CEO, Dr. Harald Stock, sparking reaction from thalidomide victims groups worldwide. In both instances, thalidomiders made their status as victims explicit in order to participate in the governance of others.

Randolph Warren, then-president of the TVAC, was a vocal participant in the 1997 public meetings on Celgene's bid to produce THALOMID™ in the United States. The initial indication was for leprosy, though the frequency as 'off-label' prescription was considered as well.

Thalidomide was, and continues to be, of huge symbolic importance to the FDA: it was the institution that prevented the drug from sale in the United States, on advice from a young medical officer, Francis Kelsey, because of peripheral neuritis symptoms encountered during clinical trials. Following the thalidomide events in the 60s, the 1962 Kefauver-Harris amendments to the Food, Drug and Cosmetics Act deeply altered the manner in which drugs were approved in the United States. The amendments required that pharmaceutical trials demonstrate both efficacy *and* safety of drugs *before* they are distributed throughout the American market. At the 1997 meetings, Warren and the TVAC asserted an ‘educational’ role, repeatedly asked Celgene: “What will you tell the thalidomide baby that inevitably will be born?” (Warren in Timmermans & Leiter, 2000, p. 56) The TVAC made evident that though they were not pleased that thalidomide would emerge again on the pharmaceutical market, they would rather have it do so with their guidance than without.

It pains us, but we have come to the conclusion, that we’re forced to prefer the regulation of thalidomide because we are so much more afraid of thalidomide being available as it is today or having it relegated to a secret world controlled by so few doctors and scientists, who we won’t disrespect, but we would rather see it in a public controlled environment (Warren in Timmermans & Leiter, 2000, p. 56).

The outcome from the hearings was Celgene’s license to produce THALOMID™ in July 1998, and the creation of the System for Thalidomide Education and Prescribing Safety (STEPS), a standardized distribution system to minimize the risk of birth defects.<sup>11</sup> The system: THALOMID™ users must employ two types of birth control, and undergo contraceptive counseling throughout their pharmaceutical tenure. Women are required to undergo pregnancy testing before being given the drug, only prescribed in 28-day intervals.

Thalidomiders did more than simply interrogate Celgene at the meetings. Warren and the TVAC had a significant impact on the packaging for THALOMID™, using their own likeness as a means to warn about its dangers. The package contains a letter from the organization and a picture of a smiling phocomelus. This tactic is consistent with the TVAC’s approach elsewhere: “Remember us... KNOW YOUR MEDICATION!” is prominently displayed on the group’s website, alongside a discussion of the drug’s international history and the mission of the TVAC. In both cases the goals of the TVAC are clear: to prevent any future thalidomide malformations. Actively engaging in the politics – and aesthetics – of victimhood is one way in which they do so. The NIH and FDA meetings on the return of thalidomide are one instance where we need to question disability studies’ disdain for questions of victimhood. I’ll return to the governance aspects of this program in the following section. To conclude this section, then, I want to discuss another, more recent historical thalidomide instance: the global reaction to the unveiling of the “Sick Child” at Grünenthal’s headquarters in Stolberg, Germany.

31 August 2012 marked the 50<sup>th</sup> anniversary of the removal of Contergan from German pharmacy shelves. On this date, Grünenthal held a press conference and unveiled their thalidomide memorial, with CEA Harold Stock providing a page-long written statement to contextualize the statue’s meaning, express sympathy for the victims of the drug, and maintain Grünenthal lack of direct responsibility for the tragedy.

The thalidomide tragedy took place 50 years ago in a world completely different from today. The international scientific community, the pharmaceutical industry and governments, legislators and administrations have had to learn a lot from it. Throughout the world the tragedy influenced the development of new authorization procedures and legal frameworks, which seek to minimize the risks of new medicines for patients as much as possible.

Grünenthal has acted in accordance with the state of scientific knowledge and all industry standards for testing new drugs that were relevant and acknowledged in the 1950s and 1960s. We regret that the teratogenic potential of thalidomide could not be detected by the tests that we and others carried out before it was marketed.

[...]

We wish that the thalidomide tragedy had never happened. It is an important part of our thinking and acting – today as in the future.<sup>12</sup>

Reaction from thalidomiders was swift. The Federal Association of Contergan Victims dismissed the memorial as a “PR measure”, one that “is supposed to signal to the public that the company still has Contergan on its agenda, without any serious effort to address the concerns of the people who have been permanently damaged.”<sup>13</sup> Others were quick to attack the presentation of thalidomiders singly as deformed children, as the product of a past medical disaster that we can do nothing about. The problems faced by thalidomiders have little to do with adolescence. Rather, they have and continue to demand that Grünenthal treat them as disabled adults, who require significant resources to live decent lives. Those resources should come, in whole or in part, from Grünenthal. “To apologize for something is one thing,” said Canadian thalidomider Paul Murphy, “To accept responsibility to those who need it is another.”<sup>14</sup>

In both the reaction to the Contergan memorial and in their actions at the NIH and FDA meetings, thalidomiders make active use of their victim status. Theirs is, to borrow two words from philosopher Annemarie Mol (1999), an ‘ontological politics’ of victimhood.<sup>15</sup> Thalidomiders are attempting to actively shape reality by shaping themselves as victims. As I suggested in the introduction to this paper, this shaping of victimhood is, somewhat, done on their own terms. In short: we cannot say that Thalidomiders are passive victims. They are active. Though they are actively demanding recognition and accommodation for their existence, they also make perfectly clear that thalidomide’s teratogenicity should be restricted to existing thalidomiders. That should be theirs alone, but they also exist as disabled persons, victims of equally Grünenthal’s exclusion as of thalidomide’s teratogenicity.<sup>16</sup> Though theirs is an active victimhood, it is victimhood nonetheless. In the final section of this paper, I want to reflect on the thalidomide case, to ask what connotations this so-called ‘active victimhood’ has for future disability studies. Can we talk about tragedy without betraying disability studies’ founding goals? I believe we can. In the following section, I tease out the relationship between the subjectivity as a measure of human existence, and the measure of tragedy in disability studies.

### **A change of subject – kind of**

I want to investigate subjectivity from three philosophical vectors. The first is Michel Foucault’s. Foucault’s interest was in the various practices in which human subjects are assembled,

described, and ordered throughout history. His project was incredibly vast, and I make no attempt to describe all of it here – tracing his influence in disability studies alone is a daunting task (see Titchkosky, 2003; Tremain, 2005). The thalidomide events can be dissected through some of Foucault's concepts. The STEPS regime, for instance, is a perfect example of what Foucault calls the anatomo-politics of the human body (in his work on so-called 'biopower'), and of a disciplinary *dispositif*, where 'risky' female bodies are shaped through technical practices shaped within a discursive formation (Foucault, 1971; 1977; 1978; Deleuze, 2007). Further, the thalidomider's engagement in the 'tragedy narrative' to shape that regime is a classic example of 'governmentality' and the government of the self and others (Foucault, 1997). This could be a solely Foucauldian story if we wanted it to be. I do not.

Why? Reading the work of philosopher Ian Hacking gives us two answers. One is because Hacking, who takes a great deal of inspiration from Foucault's early 'archaeological' approach, has some useful concepts to apply as well. Particularly apt to the thalidomide case is Hacking's discussion of 'human kinds.'

By human kinds I mean kinds about which we would like to have systematic, general, and accurate knowledge; classifications that could be used to formulate general truths about people; generalizations sufficiently strong that they seem like laws about people, their actions, or their sentiments (Hacking, 1995b, p. 352).

Human kinds unlike their natural counterparts because they are 'moving targets' – they react to what is said about them. The formation of human kinds is part of the greater process of 'making up people' (Hacking, 2002). In this instance, thalidomiders made *themselves* up as distinct from the 'thalidomide babies' discussed in popular culture and in the medical literature. Here, as elsewhere, "Making up people changes the space of possibilities for personhood" (Hacking, 2002, p. 107). Thalidomiders' active victimhood is such an instance. They are not alone: Hacking has noted similar trends of self-king-making in his discussions of dissociative identity disorder (1995a), homosexuality (2002), and child abuse (1991). In sum, Hacking and Foucault are proximate thinkers, with complimentary projects. We should not restrict our reading to the latter. This is the 'soft' answer.

Hacking gives us another answer to the 'why?' question, a reply more cantankerous than the other. In his *Mad Travelers*, Hacking argues Foucault was far more pragmatic with his philosophical concepts than some of his current interpreters' work displays.

I find this sad. Foucault carved numerous turns of phrase into ice sculptures, which had, for a moment, sharp contours. Then he walked away from them, insouciant, and let them melt, for he no longer needed them. His less gifted readers put the half-melted shapes into the freezer and, without thinking, reproduce these figures as if they still glistened in the midnight sun and meant something (Hacking, 1998, p. 85).

Hacking's use of 'less gifted' is unnecessarily ruthless, but it brings forth an important point: Foucault's project was more historical than anything else. He came up with some philosophical concepts to add richness to his histories of the present. To wrench those concepts from these narratives, to use 'governmentality', 'biopower' or 'discursive formation' outside of that history, is

to miss what is really interesting about Foucault's work. We risk eclipsing a great deal of Foucault in sketching out ahistorical, abstract 'Foucauldian' theory. He used philosophical concepts to bring us closer to history, not farther from it.

Hacking continues this line of thought – albeit in a far more productive manner – in his “Between Michel Foucault and Erving Goffman: Between Discourse in the Abstract and Face-to-face Interaction” (2004). Hacking takes Foucault's *Histoire de Folie* (1961, English translation: 2006) and Goffman's *Asylums* (1961) as an instance where the two can be read in a complimentary manner, discussing (what we now call) mental illness. Both authors are interested in making up people, he argues, but from vastly different vectors:

completely omitted by Goffman is the question of how institutions come into being, and what organizations of thought and statements have to do with our thinking of them as natural, as part more of the found order, than the order of things made by people. [...] Foucault gave us ways in which to understand what is said, can be said, what is possible, what is meaningful – as well as how it lies apart from the unthinkable and indecipherable. He gave us no idea how, in everyday life, one comes to incorporate those possibilities and impossibilities as part of oneself. We have to go to Goffman to begin to think about that (Hacking, 2004, p. 300).

There is a very important historical vector to the thalidomide story, about the ways in which the humanity of thalidomiders, and thalidomide users, has been made and remade by various governing regimes. But these long-term developments have always been steeped in situations of somatic co-presence, in Goffman's “interaction order”.<sup>17</sup> While it would be folly to ignore the historical aspects of the tragedy, the ‘just-thisness’ of thalidomider victimhood, made up in face-to-face interaction like the NIH and FDA meetings, is part of my narrative as well.<sup>18</sup> Here, Hacking not only clarifies, but also provides a horizon to Foucault's project. It is not all encompassing. In tracing how thalidomiders carve out and take measure of their own subjectivity qua tragedy, I suggest we turn to two other, (mostly) complimentary philosophies. The first is Martin Heidegger's.

It is well known that Foucault and his French Marxist-Existentialist contemporaries had very distinct philosophical perspectives on the role of history, the state, and man's essence. Phenomenology's search for the basic structures of human experience is often contrasted with Foucault's archaeological and genealogical method. In this sense, Foucault's project is opposed from the outset to Heidegger's fundamental ontology of human existence (German: *Dasein*). Elsewhere, however, there are similarities. One commonality is Heidegger's famous rebuff of *his* French philosophical counterparts in the “Letter on Humanism” (1993a). There, Heidegger is critical of how Jean-Paul Sartre adopts his fundamental ontology in the latter's existentialist (Marxist) humanism. Heidegger argues that Sartre fails to understand *his* philosophy, because his humanistic philosophy, as does Husserl's, accepts a pre-given subject as its starting point. He generalizes this argument to humanism as a metaphysical basis for Western philosophy as a whole:

However different these forms of humanism may be in purpose and in principle, in the mode and means of their respective realizations, and in the form of their teaching, they nonetheless all agree in this, that the *humanitas* of *homo humanus* is



determined with regard to an already established interpretation of nature, history, world, and the ground of world, that is, beings as a whole.

Every humanism is either grounded in metaphysics or made to be the ground of one. Every determination of the essence of man that already presupposes an interpretation of beings without asking about the truth of Being whether knowingly or not, is metaphysical (1993a, pp. 225-226).

So while Foucault traces various practices of subjectification deployed throughout practices of regulation and their associated truth regimes, Heidegger argues that subjectivity *itself* is an historical artifact of Western metaphysics. It is in this sense that reading Heidegger alongside Foucault actually brings us *closer* to history, the history of subjectivity.

For Heidegger, subjectivity fails to encapsulate the basic structures of Dasein. The difference between human Being and the ontology of the subject is called the *ontological difference*, first introduced (to my knowledge) in *Being and Time* (German original 1927, my copy translated Heidegger, 1996). In the ontological difference, we find the key to his philosophy. We can sketch it by looking at the tradition that Heidegger attempts to overcome: the 'ontology of the subject', found most extremely in the philosophy of Descartes. Descartes' understanding of 'world' in terms of extended substance serves well as a basis for physics, but not for an understanding of the specifically human way of being. The kind of being disclosed in physics is what Heidegger calls the ontology of 'objective presence'. The space/time of physics and the times and spaces closest to human existence are not identical. Humans throw themselves into past and future events through mundane action. The time closest to us is not measurable in inches and seconds, it has an 'I-can-and-will-and-have-previously' structure. "Time is the how" (Heidegger, 1992, p. 22). Similarly, the spatiality of human Being is not measured in centimeters or yards. Rather the things that are closest to us are disclosed in routine *care*, defined widely. Here we can look to Heidegger's famous carpentry example. The hammer as disclosed in routine hammering, without a second thought, is handy to us. It is a useful thing. But it will be the farthest thing from us when it shatters. It becomes a merely present thing. Useful things have a whole system of reference that we use them for. The hammer brings us closer to the family who will live in the home we are hammering-forth. It discloses our historical ancestry as toolmakers.<sup>19</sup> The useless tool is a hunk of material. The difference between the ready-to-hand hammer and the objectively present hammer is the ontological difference.

If we accept that the fundamental disclosure of human Being is found in care, we are forced to reconsider the common notion of truth. The vulgar notion of truth, *that which is in accordance with fact or reality*, is underpinned by the ontologically more prior *aletheia*: the process of beings coming into their own being, likened by Heidegger to a flower coming into bloom. For Heidegger, the vulgar notion of truth fails to account for the ontological difference. In light of the difference, the "*essence of truth reveals itself as freedom*" (Heidegger, 1993b, p. 128). *This* form of truth is not encapsulated in the Foucauldian approach, which is restricted to main in terms of objectively present subjectivity. I must emphasize that Heidegger is not *opposed* to objective presence. His opposition is in philosophies that presume that this form of being is an adequate description of human Being. His opposition is to its unthought ubiquity and overextension. In order to pursue scientific enterprise like physics, however, we need to consider the contents of the world as measurable chunks of time-space, energy and matter. That is, the fundamental time-spaces of care and concern, and the basis of truth as *aletheia*, must be bracketed in order to *do*

physics. This is the difference between ontic and the ontological deliberations—the ontic does not broach the fundamental question of Being. In this sense, we can say Heidegger’s philosophy (of science) is a philosophy of (scientific) measurement.

Heidegger offers us some philosophical insight on the thalidomide events introduced in the previous section. We can use his philosophy to talk about how the times and spaces of thalidomider Dasein are made objectively present in order for them to claim the expenses that they incur because of thalidomide’s residual effects on their bodies. Two examples come from reactions to the sick child. A spokesperson for the German victims association used the example of expensive dentures adapted for grasping items, because of non-existent hands.<sup>20</sup> Secondly, Freddie Astbury of Thalidomide UK discussed necessary changes to cars, costing upwards of £40,000.<sup>21</sup> Thalidomiders *make* themselves into subjects in a world of objective presence to claim shared humanity with others. Here humanism is *deployed* when second order descriptions of Being are used to establish commonality, for compassion or human-rights-based arguments for compensation by Grünenthal, governments, or both. While Dasein is always indivisible, the body-subject can be described at the second order as ‘lacking’, ‘deformed’, or ‘worthy of compensation.’

Obviously, not all disclosures of thalidomider being are optimal. Thalidomiders have made evident that they do not wish to be solely disclosed as victims of medical tragedy, but rather as living, breathing disabled persons capable of self-governance when properly accommodated. They can speak for themselves, while ‘thalidomide babies’ cannot. In Heidegger’s “On the essence of truth,” he elaborates on the ontologically primary basis of truth as *aletheia*, first introduced towards the end of *Being and Time*’s first division. As stated above, the version of truth as disclosedness is closer to Dasein than the derivative mode of truth, the accordance of fact or reality with a state of affairs. In the “essence” essay, Heidegger suggests that *aletheia* is the process of beings coming into their own Being. They emerge to Dasein *as beings* in truth *as process*. “The essence of truth reveals itself as freedom” (Heidegger, 1993b, p. 128). The thalidomider’s self-presentation is also a manner of freedom. It is denied to them when Grünenthal described them as past victims of solely medical tragedy. It is *gained* when they are permitted to disclose their being on their own terms. Here, as elsewhere, measures of truth are measures of freedom.

I want to conclude this section, and this paper, with a discussion of the Actor-Network Theory (ANT) tradition in philosophy, sociology, and disability studies (Callon & Rabeharisoa, 2004; Mol & Law, 2004; Schillmeier, 2010). While both Foucault and Heidegger wish to sketch the history of Being, Actor-Network Theory provides an empirical corollary to these investigations. It began in empirical laboratory studies, and despite being extended to sociology in all forms, has not lost this empirical grounding. Whereas Heidegger (1993c) focuses on how technology enframes man’s essence, ANT asks us to pay meticulous attention to that framing as a network achievement. Unlike Foucault and Heidegger, Actor-Network Theorists follow actual people around. Here I will focus on Michel Callon and Vololona Rabeharisoa’s work, following the *Association française contre les myopathies* (the French muscular dystrophy association, hereafter AFM) around (2004; 2004; 2008). Here the tripartite themes of subjectivity, disability and measurement intersect.

Rabeharisoa and Callon’s “Patients and Scientists in French Muscular Dystrophy Research” (2004) make evident that the AFM organization is deeply linked to measurement. Since its origins in 1958, the association has been devoted to the measurement of muscular dystrophy, both directly and indirectly through research funding. At its inception, AFM clients and their parents developed

so-called 'proto-instruments' to collect data on the wide variety of conditions that would later be named muscular dystrophy. They actively shaped the lives of those with these disorders, extending them in some cases, which allowed new knowledge to be gained about the conditions. People were living longer, and more was being discovered about the disease's effects.

One of the association's first contributions was to make an inventory of patients. This required systematic and repeated inquiries, especially in hospitals, as well as the organization of the press campaigns. One of the consequences was that groups of patients were able to organize the collection of DNA. [...] By mobilizing proto-instruments, the patients and their families put themselves in a position to create quasi-formal, transportable, accumulable and debatable knowledge (Rabeharisoa & Callon, 2004).

The patient-controlled research network established by the AFM remains as such today. While Rabeharisoa and Callon cite the instance as one of the 'co-production of scientific and social order', it also touches on the theme of subjectivity: MD patients become both subjects and objects of the research enterprise.

In "Gino's lesson on humanity: genetics, mutual entanglements and the sociologist's role" (2004), the two sociologists examine a 'blip' encountered within their research on the AFM, the actions of a man named Gino. Both Gino and his brother have been diagnosed with muscular dystrophy. They could not be more dissimilar past this. Léon, Gino's brother, is active in the La Réunion island chapter of the AFM, and refers to it frequently when interviewed. He can also speak volumes about muscular dystrophy's genetic transmission. Gino is noticeably silent throughout his interviews – on both the chapter, whose events he does not attend, and genetic testing that might prevent passing the disorder through his bloodline. Callon and Rabeharisoa meditate on Gino's silence, asking what types of humanity are irrupted onto those undergoing the sociological interview. Genetics is a public assemblage, with which Gino is forced to reconcile. Like any public arena, it presupposes action that must be taken on behalf of those who it describes. Parents with muscular dystrophy must get genetic testing. They must rationally consider the chance that their children will be born disabled. To ignore this fact is, in sum, inhuman, and such is sociology's reaction to subjects like Gino who ignore them. Biology and the ethical do not simply intersect here. They unify.

After hearing Gino's lesson on bio-ethics, and after leaving Léon, we wondered what the profile would be of a sociology that strove to promote the emergence of several ways of behaving humanly? It would need to be attentive to local moral options in their confrontation with morals that claim universality; it would need to be sufficiently dull to be content to record singular projects as they emerge during such confrontation, being extremely wary of any tendency to construct general principles and synthetic frameworks (Callon & Rabeharisoa, 2004)

There are obvious similarities between Heidegger's work and Callon and Rabeharisoa's. So too are there similarities between their work and the later Foucault, in the manner that persons constitute themselves as ethical subjects (as acknowledged in the paper). For us, the important point of commonality is that subjectivity – be it sociological or philosophical – does not fully encompass the

human way of being. It is not pre-existing, but is made. Sociology itself cannot claim to be without such a framework.

Looking to the thalidomide events, I believe that disability studies, too, irrupts a particular form of subjectivity unto those researched. Disabled persons are ‘research subjects’, with all of the philosophical baggage that term connotes. While authors like Michael Oliver may seek to “Change the Social Relations of Research Production” and place the reins into the hands of the disabled person’s movement (the title of Oliver, 1992), they cannot avoid thrusting a whole set of assumptions onto disabled persons-as-disability-studies-subjects. It, like any other description of human activity, must come to terms with the problem of the ontological difference. One of those assumptions is that good disabled people don’t ‘do’ tragedy. It is reactionary and it is oppressive. It is a Bad Thing. As I have argued above, tragedy comes in many forms. While some are imprinted from without and do a disservice to those so labeled, some are activated from within, as seen in both the NIH and FDA meetings, and the global reaction to the “The Sick Child.” In actively enacting tragedy as a description of their own lives, they are deploying a specific measure of human existence. My very basic argument is that disability studies should support them in this role.

In this paper, I have suggested that disability studies has been anti-metrological from its outset. It sought then, as it does now, to research the way that disability is produced, coordinated and governed, with an eye to improving the lives of those so examined. Historically, tragedy has been seen as an obstacle to overcome, something in the way of disabled existence. In the second part of this paper, I gave a brief account of the global thalidomide tragedy. Two key moments were isolated, and in these instances, thalidomiders constituted themselves as victims of tragedy. They did so as currently disabled victims of neglect, not the result of a long-gone tragedy that they could ‘wish never happened’. They also did so to prevent tragedy anew. In the third section of this paper, I turned to some philosophical perspectives on subjectivity to ask how disability studies might take active-victimhood seriously. I looked to three, though I undoubtedly could have looked to more. By reading tragedy through these three lenses, I believe I shed light on new points of connection where many would see none. In sum, I believe that a reconsideration of tragedy allows us to better address and redress the experience of disability. This is, as we have seen, the aim of disability scholars worldwide. My hope is that other forms of activist-research will take tragedy seriously as well, as a *source* of humanity, not merely its repression.

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### Endnotes

- <sup>1</sup> This work generously supported by the Social Sciences and Humanities Research Council of Canada. An earlier version of this paper was presented at Workshop: Regimes of Calculation and Global Governance, held at the Balsillie School of International Affairs, Waterloo, Ontario, September 19<sup>th</sup>-20<sup>th</sup>, 2013. My thanks to Aaron Henry and Branden Miller for their insightful commentary on the paper and subject matter.
- <sup>2</sup> This theme is addressed more fully after *The Politics of Disablement* in Oliver (1992).
- <sup>3</sup> The ‘medical model’ or ‘medicalization’ is, of course, a theme frequently found outside disability studies. For classic studies written prior to *The Politics Of Disablement*, see Szasz (1974), Illich (1975), and Conrad (1980).
- <sup>4</sup> Titchkosky (2001) uses the term as a reference to the “unmarked categories of persons that are culturally regarded as “definitive human beings” [...] It also means being regarded as the “type” of person who is generally intended and expected by the normal order of interaction, the physical environment and the structures of knowledge production.” In this term we see her influence by Erving Goffman and Dorothy Smith meet.
- <sup>5</sup> In discussing the ‘tax credit verification form’, Titchkosky is referring to the T2201 Disability Tax Credit Certificate (Canada, 2011), an obligatory passage point to a variety of tax provisions for disabled Canadians. For a phenomenological perspective on the form, see my Abrams (2013)
- <sup>6</sup> Oliver’s account makes strange use of Foucault, attempting to use his historical analyses to bolster his historical development of the prevalent ‘ideology of individualism’. For an alternative account of modern medicine’s underlying ideology as a style of reasoning, see Osborne (1998).
- <sup>7</sup> I use ‘interaction order’ in reference to both persons and things interacted with, as per the actor-network tradition, as discussed in section three below. This use is certainly more catholic than Goffman’s, who for the most part restricted his investigations to moments of co-presence, as in *Interaction Ritual* (1967), and his presidential address to the American Sociological Association (1983).
- <sup>8</sup> The preferred term now is ‘client’, in lieu of ‘patient’. I worry the use of the latter might suggest the medical encounter can be freed from hierarchy with only nominal change.
- <sup>9</sup> For a more robust review of the variety of “malformations” – their term, not mine – see Ghobrial and Rajkumar (2003).
- <sup>10</sup> Timmermans and Leiter (2000) examine the meetings in extensive detail, and serves as the basis of my account, a mere summary of their hard work.
- <sup>11</sup> A similar system now exists for the distribution of the drug in Canada, “RevAid”, for both THALOMID and REVLAMID, the trade name for thalidomide derivative lenalidomide. Celgene produces both. Information can be found online at [www.revaid.ca](http://www.revaid.ca).

- <sup>12</sup> The entire statement can be found in German and English translation at Grunenthal's Contergan site, <http://www.contergan.grunenthal.info/>. I contacted Grunenthal for a picture of the statue to include with another manuscript (Abrams, forthcoming) on the memorial, but was denied. One wonders about the intended benefit behind the production of a memorial hidden from public view. Thankfully, a quick Google image search for 'thalidomide sculpture' will yield the "The Sick Child."
- <sup>13</sup> <http://www.reuters.com/article/2012/09/01/us-germany-thalidomide-idUSBRE88004D20120901>
- <sup>14</sup> <http://www.cbc.ca/news/world/story/2012/09/01/thalidomide-apology.html>
- <sup>15</sup> Though Mol wants to read ontological politics through an actor-network theory perspective, Oksala (2010) does so through a Foucauldian one. Below I add Martin Heidegger, to carve a tripartite understanding of subject formation.
- <sup>16</sup> As disabled persons the TVAC is member to the Council of Canadians with Disabilities, an organization that is founded to promote the same human rights, social model approach found in Oliver's work, above. See <http://www.ccdonline.ca/en/>
- <sup>17</sup> I borrow this phrase from Harold Garfinkel (1967). Britt Robillard, a student of Garfinkel's, makes a similar point about how moments of anger should not be eclipsed by the history of anger, in his *Anger In-the-Social-Order* (1996).
- <sup>18</sup> An example: Timmermans and Leiter discuss how Warren and the TVAC were the only members present at the meetings who would address abortion, and its relation to the STEPS program, head on. The transcripts analyzed showed reluctance, awkwardness and unease on the part of the non-thalidomiders to discuss abortion of deformed fetuses in front of Warren and the TVAC. They changed the subject. A historical approach to awkwardness does not have much use here, without paying attention to the just-this-ness of the interaction order at the meetings.
- <sup>19</sup> We'll have to ask our anthropological colleagues if this definition is still up to date – my hunch is that it is not.
- <sup>20</sup> <http://www.dw.de/too-little-too-late-say-thalidomide-victims/a-16214497>
- <sup>21</sup> <http://www.thesun.co.uk/sol/homepage/news/4515806/Thalidomide-makers-apologise-50-years-after-drug-caused-birth-defects.html>