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‘Disability Solutions’: Subjectivity and the Business of Disability

I came to Easter Seals’ office in January as an alumnus. Having spent several years as a youth volunteering as their district ambassador, then called the “Timmy,” and thus having already attended numerous fundraising events on the organization’s behalf, my placement early this year was something of a homecoming. At any rate, I viewed it as such when I signed up, feeling eager to give back to an organization that I felt had given me a great deal, including covering the costs of my first few wheelchairs, without which I may never have developed a sense that mobility is a human right, or so my thinking went. In other words, I came into my placement from a peculiar standpoint as a former Easter Seals child: someone who viewed the organization’s work, prior to having undergone any careful consideration of its mission statements, as undisputedly positive. Without them, I thought, I would not have been granted the tools to enable me to pursue the paths I intended to follow, and to eliminate the barriers in my way. I was full of such metaphors for independence – some of them my own.

I begin with this preamble about my prior experience with the Easter Seals Society, now Easter Seals Ontario, because I feel it helps ground my subsequent concern as I came to examine the ideological foundation upon which the organization’s rhetoric of independence, which I once assumed was neutral and repeated, rested. Moreover, it elucidates the fact that when I began volunteering there, I did not expect to find myself wondering if certain policies were structured as they were to serve the organization’s donor base of individual and corporate sponsors as much

as the particular needs of their clients. If I came in expecting an organization dedicated to making the world accessible for children with physical disabilities – a utopian ideal I naively projected upon them as a youth – I found that their services, though no less benevolent in their administration, were instead directed primarily toward fitting the disabled within their inaccessible world – finding individual solutions for such problem cases.

The difference is significant, and indicative of a particular understanding of what constitutes disability for the organization – whether it is seen, for instance, as a physical problem or a socially constructed phenomenon. In an article on the theoretical intersections among disability, human rights, and public policy, Marcia H. Rioux and Fraser Valentine distinguish between social scientific and social pathological approaches to disability. The former approach, they argue, is rooted in an assessment of disability as an individual's comparative incapacity in relation to an able-bodied norm (49). Social responsibility is limited in this view to promoting “primary prevention” (50) initiatives, marking disability, often in biblical terms of affliction, as something to eliminate or cure, lest it drag down the general populace or the economy. The costs of disability, moreover, are framed as a social burden: for the public to account for the disabled financially is to incur costly expenses for individual medical problems. As such, increased inclusion of the disabled in such environments as the workforce becomes a private rather than a public responsibility – a question for organizations like Easter Seals to field on a local level, rather than a question of human rights. In all of these cases, the individual is framed as the primary point of intervention, to be rehabilitated to an economically viable, self-sufficient state.

Against this view, Rioux and Valentine offer the social pathology model, which considers disability not as an individual misfortune, evaluated with respect to the degree to which a given person deviates from the norm, but rather as a consequence of how a society is organized, and

how its environments are structured. In this view, rehabilitative initiatives target not disabled individuals themselves but rather the social standard against which a potentially able-bodied person is measured and deemed disabled. To be disabled, according to this view, is to be restricted by the socially constructed, but still physical, barriers in one's environment. To address disability, or to go even further and purport to cure it, is to target aspects of a given environment as being structurally inaccessible. Tellingly, doing so does not entail marking a person incapable of accessing a staircase, for instance, as disabled, and placing the onus on him or her to accommodate to that staircase. Rather, it identifies the staircase as the problem, marking its inaccessibility as a disabling factor. As such, prevention is seen not as the early biological detection and elimination of disability, but rather as the elimination of obstacles that would socially construct disability; disadvantage, moreover, "falls within the public domain" (53).

In this paper, I will read Easter Seals Ontario's policies primarily in relation to these two prevalent constructions of the disabled subject, as either physically deviant from the norm and thus in need of rehabilitation, or socially constructed as lesser in relation to often disabling standards, which may themselves be corrected. Easter Seals depicts itself as a third party funder that raises money to enable children, youth, and young adults with physical disabilities to develop their potential and to achieve a level of hitherto unrealized independence. In providing financial aid to secure such equipment as wheelchairs, walkers, and communication devices, the organization believes, they are providing their base with what they call "disability solutions," perhaps echoing IBM's claim to offer "business solutions." Implicit in this understanding of disability, however, is the assumption that it is a problem to be solved, and that this problem's source is an individual's physical deviation from the ideal, which must at some point be corrected for the individual to fully integrate within society. The means to correct that deviation,

moreover, is identified as the process adopted by Easter Seals, whereby a child's potential is unlocked through the addition of assistive technology.

This understanding of disability fails to address the disjunction between the organization's benchmark of independence, achieved once that potential is realized, as the solution to disability, and the reality of genetic diversity – the fact that neural tube defects are common, if not always visible, rendering some disabilities more standard than the able bodied state the organization aims to cultivate. It also fails to account for the environmental factors that define disability: the real and metaphorical staircases that inhibit a person's successful negotiation of his or her environment. Moreover, it speaks to the rationale behind Easter Seals' mandate, implying that the organization's focus on helping children to achieve independence stems from its belief that, inhibiting sociopolitical and environmental factors notwithstanding, it is a disabled individual's responsibility to realize his or her potential against the odds.

Easter Seals' part, in other words, is not to level the social playing field so much as to assist and even train the children and youth they serve to better play within its clearly demarcated bounds. As such, their services are focused not on addressing concerns about why a given environment is disabling, which is generally taken for granted in their policy documents, as in their aim to create in a fully wheelchair accessible camp a hallowed space with "no stairs and no stares." Indeed, rather than questioning why such a place ought to be seen as the exception rather than the norm, a sanctuary and retreat rather than the world as it should be, Easter Seals treats the utopian space of camp as a training ground to prepare its youth to face the real, and unquestionably more inaccessible, world. It is once again the child's duty, with considerable financial assistance from Easter Seals, to take what he or she learns at camp into the world beyond. It is not the world's responsibility to sensitize itself to the child.

The central question I will thus address is why the Easter Seals mandate is focused on solving disability at the site of the disabled subject, and why there is so little emphasis, in their policies, on how disabled subjects are constructed, by inaccessible environments and policies, in terms of their physical lack relative to able-bodied norms. Why is its focus on solving disability on an individual level, so that a person might better participate in society – for instance, granting a wheelchair to get a person to work – rather than on challenging social barriers that render an individual's experience disabling? In other words, why might Easter Seals be so hesitant to channel their services through the social pathology model, in which structural barriers in a given environment, rather than disabled individuals themselves, are treated as sites for intervention? Moreover, could this move to render disability a detachable appendage that, in its removal, reveals a disabled individual's human potential, be attributed to the organization's need to solicit funds from the private sector – to speak the rhetoric of liberalism and of the job market?

In addressing these questions, I will first consider traditional idealist and liberal conceptions of the essential human, in sources such as Plato's *Gorgias* and Jean-Jacques Rousseau's *On the Origins of Human Inequality*, then chart the critique of these attitudes by contemporary disability theorists. From there, I will examine Easter Seals' emphasis on cultivating independence through these theoretical lenses. My principal aim, then, will not be to expose Easter Seals or thoroughly critique its policies. Rather, I will develop a sense, through these varying perspectives on ability and disability, and the ideological foundations upon which they rest, of why Easter Seals must frame disability as an individual pathology at all, in order to solicit funds, while considering whether there might not be ways for non-profit organizations to pursue an alternate, environmentally-based, approach. My question is thus two-pronged: where is this conception of disability as something to be cured on a case-by-case basis through the

achievement of independence coming from, and can it be reframed in a wider sociopolitical context that puts greater emphasis on the world as a site for intervention?

Before considering that question in full, one might examine the cultural roots of this tension between viewing disability as either an individual corruption of the ideal or a social creation and, as such, a social responsibility. Insofar as the former view, consistent with Easter Seals' mixed mandate to do away with disability in the abstract through disability solutions while helping individuals lead better lives is largely Platonic, I will begin by examining Plato's construction of goodness as an ideal, preceding the body, and serving as a natural state to which humans might aspire. What I would emphasize here is the way in which the Platonic tradition can be seen to establish the conditions for the as-yet undeveloped social scientific or medical model of disablement by conceiving of a natural state that exists prior to individual corruption.

In *Gorgias*, the glories of this natural state are expounded upon through a debate on the ethical dimensions of rhetoric, as an obscuring agent that renders objective truth and fundamental goodness unclear. Socrates links rhetoric with cookery insofar as it aims to produce pleasure without having studied "the nature of pleasure or its causes" (311). Concerned only with ends and not essences, rhetoric is therefore a second-order form that yields pleasure rather than goodness, bringing forth only derivatives of an essential – the good. If rhetoric obscures, truth inheres, and humans, as Socrates points out to Callicles late in the dialogue, are good not because they have been convinced to act well by hollow rhetoricians, but "by reason of some excellent presence within" (318). The good can therefore be defined as "a certain order present in each existing thing" (318), and to cultivate one's goodness is thus to develop oneself in an orderly

manner, with respect to this preexisting ideal. It is to attune oneself with the ideal, rather than fall further from its standards.

This notion of the good as variously the nature and cause of pleasure as well as an excellent presence and order that exists prior to the individual is articulated more fully towards the end of the dialogue, in Socrates's parable of the gods attempting to judge the souls of the dead. Death, Socrates infers, is the separation of body and soul, and "when a man is stripped of the body, all the natural affections of the soul are laid open to view" (337). Once the obscuring effects of the body are purged, the natural soul may thus be evaluated in its pure form. Significantly, for the natural affections of the soul to be "laid open" – in other words, rendered intelligible, viewable, and usable – the body, as a second-order vestment that would mask the natural, must be stripped away.

This construction of the good as a natural order, prior to individual humans' existence, is consistent with Plato's position on truth as an ideal form. Moreover, its implication that essences precede individuals, and that individuals might therefore be viewed in accordance with those pre-established ideals, is the basis for the dominant strand of Platonic thought inherited by subsequent western discourses on the body. In *Invention as a Social Act*, Karen Burke LeFevre explores the prevalence in contemporary composition theory of this Platonic view with respect to rhetorical invention. In this view, she observes, an individual is thought to possess a still uncovered reserve of "innate knowledge" (11). Writers search within their inner recesses to uncover a natural truth pre-invested but obscured by the material world of images (15) – in *Gorgias*, the material vestments of the body. This search is a quest to find stability – an inalienably human truth that transcends the particular, which, to use the example of souls stripped of their bodies, may be the features of a deviant body that mar the ideal.

As such, what we find in Plato is a way of thinking about individual experience in relation to a permanent, objective, and essential set of characteristics that precede the self. Platonism results, therefore, in an understanding of all phenomena in relation to an abstract, perfect ideal. Its acceptance as an ideology, moreover, has direct political consequences. In art, as LeFevre notes, it results in a view of the artist as developing his or her essential self at the expense of the world (17). In policymaking, it places absolute good at the top of a hierarchy, making it a potentially unreasonable standard, and thus a goal that can be discounted because it simply is not achievable. Platonism's allegedly objective but largely undefined claim to a natural state invites policymakers to fill in the blanks as required, in deciding what values, and what bodies, constitute the standard.

This inquiry into the western bias toward the essential, self-sufficient human may be advanced from Platonism to classical liberal thought, through some consideration of Jean-Jacques Rousseau. Rousseau, too, taps into the abstract idea of a natural human state in his essay against social inequality. Early in his discourse, Rousseau derides the man of society's "soft and effeminate way of living" (11), dependent as he is upon tools to enact simple tasks crucial to survival. In contrast to this socially weakened man, he proposes that "natural man" (10), provided he develop an instinct for self-preservation, finds his wants "completely supplied" by virtue of being "issued from the hands of nature" (6). Although the rest of his treatise traces a hypothetical chronology of social inequality, which he reads not in history but in the "book of nature, which never lies" (4), Rousseau does not address questions of natural inequality beyond this implication that nature doles out its necessities in a fair measure. The suggestion here is that dependence upon social tools for survival is both a sign of weakness and a corruption of human,

that is to say, masculine, nature; those who are not supplied by nature directly must rely upon the pity of others for their continued survival in a world they are not cut out for, so to speak.

Questions inevitably arise here about what precisely constitutes the shared essence of humanity from which Rousseau calls for equality. An examination of his language, in fact, reveals a narrow view of the natural as a solid form, not unlike the essential human soul Socrates describes. Indeed, in the first part of Rousseau's discourse, he notes that nature treats children as Sparta treated the children of her citizens: "those who come well formed into the world she renders strong and robust, and destroys all the rest" (6). We might hear in this invocation of forms and strength another essentialist argument for an ideal state of humanity, stripped of obscuring cloaks. To come well formed into the world, as Rousseau constructs it, is to be born of inherently good human stock.

This notion of being made strong or weak by nature marks a blind spot in Rousseau's study, insofar as his myopic focus on the ills of socially constructed difference and his neglect of the repercussions allegedly natural physical disparities have on inequality renders the former a crisis to address immediately and the latter an unfortunate but inalienable fact. Critics like Carolina Armentieros discuss Rousseau's ideological motivations in this light, arguing that as he constructs it, "natural right is a matter of individual self-preservation" (110). To be natural is to be physically fit enough to pursue one's highest course – a classical liberal view of independence as survival on one's own terms. Indeed, to depend on tools rather than on oneself is to be incapable of advancing on one's own terms.

What, though, is to become of those who do not develop that "robust and almost unalterable habit of body" (6) with which natural man is endowed? Surveying Rousseau's use of allegory in his *Confessions*, Steinar Bøyum finds numerous constructions of substandard

physical ability, defined again in relation to the ideal of robustness, as a mark of society's alleged effeminacy and childishness. Disability is thus treated as a marker for society's inadequacy – and, implicitly, femininity – when stacked against the individual determination afforded by a life in nature, where equality lies in reach, provided one possesses the resources to thrive on one's own. Bøyum cites in this regard an anecdote wherein the state is symbolized by a boy, “who on the one hand is a child, the most natural of beings, but also a cripple, used by Rousseau as a symbol of the deformation of nature” (72). For Rousseau, then, the natural is largely an embodied ideal, bound with ideas about unhindered masculine self-advancement. If Rousseau uses the disabled to attest to the horrors of nature gone wrong elsewhere, the felt absence of disability in his discourse on the origins of inequality reveals in a photonegative everything the liberal subject is not: dependent, static, and incapable of progress.

This construction of the disabled subject as a corruption of core liberal values has direct political stakes. To look forward from Plato's construction of the body to its implication for disabled bodies in particular, discourse centred on objective ideals, as Tanya Titchkosky observes in her analysis of the rhetoric of social policy, constructs disability wholly in relation to that standard, as a comparative lack of ability (61). Dianne Pothier and Richard Devlin suggest a link between this Platonic construction of disability as a corruption of the ideal, and liberalism, which conceptualizes disability as misfortune, and privileges normalcy over the abnormal (2). This normalizing impetus, they argue, stems from liberalism's “insufficiently relational understanding of the self” (8), and its tendency to structure progress as the ideal, a philosophical position resulting in policies oriented toward an “elimination of the defect” (9). The result is a form of “citizenship minus” (2) – a disabling citizenship. Such is the idealist-liberal legacy.

Although their tone is different, and their ends more benevolent, insofar as they offer the tools Rousseau eschews as childish and effeminate, I believe one might also find a somewhat Platonic and Rousseauian construction of disability as negative citizenship in Easter Seals' view of their services as enabling the disabled to become their fullest selves. As such, one finds in these standard humanist constructions of essence a platform for an individualist view of the self as perfectible, which resonates with the move to privatize disability in the social scientific approach. Indeed, these sources demonstrate that there is a long tradition in humanist discourse of measuring individuals according to their ability to fulfill an often hazily defined human standard, whether it be innate goodness, in Socrates's case, or natural equality, for Rousseau. That standard, moreover, comes to bear directly upon bodies that fall shy of the norm.

Poststructuralist thinkers like Michel Foucault and Susan Bordo have responded to this conceptualization of humanity as striving to attain its greatest self, examining its implications for the social construction of the deviant body as a site for rehabilitation. In his seminal book *Discipline and Punish*, Foucault offers a genealogy of the modern prison system, beginning with a historical overview of the turn from late eighteenth century constructions of penalty as public spectacle to the early nineteenth century notion of the prison as a mechanism for disciplining and rehabilitating the body. The body, he proposes, is directly involved in the political field: power relations "invest it, mark it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs" (25). So too does it become, under the new system, a force of economic production, useful only if "it is both a productive body and a subjected body" (26). In this new conception of discipline, the offender's deviations are not marveled at as if in a grotesquerie: they are smoothed out. Security measures are therefore taken "not to punish the offense, but to supervise the individual, to neutralize his dangerous state of mind, to alter his criminal tendencies, and to

continue even when this change has been achieved” (18). The goal of the new prison is thus not far from the factory assembly line – to transform the particular body into the ideal subject.

Susan Bordo takes up Foucault’s critique of this notion of the body as something reparable in accordance with a pre-established norm and applies it to the social construction of female bodies in her book, *Unbearable Weight: Feminism, Western Culture, and the Body*. In a chapter on eating disorders, she begins by defining the body as a “medium of culture” – a surface on which “the central rules, hierarchies, and even metaphysical commitments of a culture are inscribed and thus reinforced through the concrete language of the body” (2362). She goes on to observe, with reference to Foucault, that bodies are shaped not primarily by ideology so much as by habits that bear the mark of that ideology, which becomes more indelible with each repetition, impressing the body “with the stamp of prevailing historical forms of selfhood” (2363). Those prevailing historical forms then become as entrenched as Plato’s ideal form, rendering the pursuit of the elusive ideal of femininity in particular, through bodily reform, “a pursuit without a terminus” (2363), insofar as the ideal can never be reached. Through this process of regulation, self-monitoring and bodily discipline – which, as a rule, must be interminable – female bodies become docile; indeed, she observes that “[t]hrough these disciplines” – the normalizing routines of dress and diet, enforced through habit – “we continue to memorize on our bodies the feel and conviction of lack, of insufficiency, of never being good enough” (2363).

It should be noted that Bordo is referring specifically to the disciplining and normalizing processes impressed upon female bodies in modern consumer culture. All the same, her analysis of the insidious method by which cultural hierarchies are imprinted upon the body, rendering deviant individuals that fail to match the ideal as lacking or insufficient are, I believe, a helpful starting point for disability theory’s own critical approach to the liberal paradigm. Both Foucault

and Bordo give a sense first, of how this dominant western paradigm might render the disabled body calculable and thus reparable, and second, how these subtle pressures upon the body to become productive, in Foucault's case, and standard, in Bordo's, might play out with additional force once disability is a variable. As such, both offer an account of how disabled bodies might be constructed as the preferred site for intervention in solving the problem of disability.

Disability theory has taken up this line of inquiry from poststructuralist thought. Leonard Davis's "Constructing Normalcy," an examination of the social construction of the disabled body in Victorian literature, offers both a clear line from Foucault and Bordo into the production of the disabled body as well as a historical overview of the concept of normalcy. Davis links the social construction of disability to early nineteenth century industrialization, focusing on the mid-century turn toward determining social and bodily norms through modern science (3). He traces the concept of the norm to Platonic notions of essence, proposing that while seventeenth century constructions of the ideal as a divine "mythpoeic body" (4) did not insist upon the public's conforming to that aforementioned impossible standard, its later revision as the norm, with the advent of modern statistics, carried an evaluative impulse. To be normal was now as necessary as to be ideal was once desirable. If the ideal was once an unattainable state, then, rendering all who fell short of its mark human, from the nineteenth century on, the norm fast became a standard to which all must aspire, and by which all must be assessed. The realization that "a population could be normed" (6) resulted in the imperative to ensure that it *was* normed.

In her article "A Genealogy of the Disabled Identity in Relation to Work and Sexuality," Rose Galvin maps the lineage of this pressure of normalization as it enters the workforce, contextualizing disabled identity in relation to processes of modern industrialization. She finds in liberal policy initiatives like rehabilitation the terms that "maintain the framework of

normalization” (499) by defining disability as a counterpoint to the norm – a corruption of Davis’s mythopoeic body’s modern equivalent. She locates this impetus in capitalist ideas about work, arguing that cure-driven initiatives “aim to rehabilitate or ‘normalize’ people with impairments” (501). The goal is thus to render the disabled capable of participating in the workforce so that they might “develop the qualities of self-sufficiency, health, wealth and consumerism that define the ideal citizen” (501), and, one might add, to wean them off financial support systems. It is at this point that the Platonic construction of essence as that which precedes the particular enters a sociopolitical discourse concerning the disabled, rendering it not a public responsibility – the logic being that disabled bodies are merely statistical anomalies or individual outliers – but rather, a matter for charitable organizations to address.

The result is often an approach that targets the disabled body as something to rehabilitate to that prior, normal human state. Robert McRuer identifies the essentialist background of the ideology of rehabilitation as especially problematic in cases of congenital disability. Though he grants that early postwar rehabilitation initiatives may have stemmed from a benevolent impulse, to return wounded soldiers to their supposed former state of social viability, he opposes the extension of this kind of helping into “curing” (109) disabilities that are as innate to the person who possesses them as one’s functional legs are to an able bodied person. Here, rehabilitation takes on a dark ideological motivation, its restorative work aimed at repairing what was only socially constructed as damaged and in need of repair in the first place. Yet, as he observes, the fact that “the state ‘assumed prior and normal’ actually follows the production of bodies that could be comprehended as coming first has not kept the rehabilitation initiative from functioning efficiently for almost a century” (111). Notwithstanding the absence of a logically consistent

explanation for whether disability is socially constructed or physically inherent, the language of rehabilitation has become common in approaching all kinds of disability.

McRuer is not alone in locating an essentialist impulse in this alleged restoration of disabled bodies to an ideal state they never possessed, and others have implied a connection between its targeted result of an able society and the similar aims of eugenics. In his *History of Disability*, Henri-Jacques Stiker observes that the rehabilitation initiative bolsters the essentialist impulse for an alterity-free society where “identicalness reigns, at least a rough identity, a socially constructed identity...of which citizens can be convinced” (131-32), recalling Foucault’s productive and subjected body, stamped free of its idiosyncrasies. Pothier and Devlin argue as well that as long as a discourse of rehabilitation that conceptualizes disability as misfortune dominates, the disabled will be fixed at the bottom of a “hierarchy of difference” (10).

James C. Wilson has followed this line of inquiry into the sciences, where the Human Genome Project’s metaphor for genetics as textuality renders disability a typographical error – a blip to be corrected with a keystroke or two, lest the book of life appear flawed. As this metaphor is put into action, geneticists are constructed increasingly as editors, working on the perfect master text, and adjusting if not deleting any flaws in the “genetic instruction book” (68), which would consist of diseases, disabilities, or other abnormalities. Genetics and molecular biology, he summarizes, are thus “constructing a model of disability as flawed genetic text in need of rewriting” (68), rendering the work of the biomedical community as nothing short of attempting to “amend, delete, and correct the defective texts of disabled bodies” (69), to restore those bodies to humanity’s “fundamental essence” (70). The adoption of either the medical or social pathology approach to disability, these thinkers demonstrate, has direct political stakes.

These lines of social and political theory can be traced in the policies that guide Easter Seals' services, which are generally directed toward ensuring a child with a physical disability's independence. Easter Seals' focus on independence begins with their purpose:

Easter Seals Ontario began in 1922 as a vision to create a better life for children with physical disabilities. Today, Easter Seals continues to offer programs and services to help these children achieve a greater level of acceptance and independence. Families rely on Easter Seals to help purchase expensive equipment needed for mobility and communication, send kids to camp and other recreational programs, and provide access to information and resources.

There is still much more to do.

Central to this assertion of what the organization does, and what they will continue to do as long as some children with disabilities still struggle for "acceptance and independence," is the implication that their services are to act as a gateway. The children they support presumably already pursue acceptance – by whom and for whom is left unclear to the reader – and independence when Easter Seals enters with helpful "programs and services," namely camp and mobility equipment. That Easter Seals is to act as a support network backing a pre-existing pursuit of self-realization on the child's part becomes clear from this insistence that the equipment they help supply is both "expensive" and "needed," and thus, currently inaccessible, but essential to a child's success on his or her own. The underlying assumption here is that to get through the world without extensive support from their families – who, because they "rely on" Easter Seals, are conceived as being burdened to some extent by the weight of these enormous costs – children with disabilities need an initial financial push. That push will consequently instill in them both the conditions and the drive to achieve on their own terms.

Although this formulation of disability as a financial burden may be partially accurate, insofar as many families do struggle to cover costs of equipment that facilitate accessibility, and insofar as a child's ability to function in various environments without strict dependence on relatives would no doubt be preferable to the alternative, it is not without its limitations. Of particular note is the suggestion that to create a better life for children with physical disabilities is necessarily to move them toward independence. There is a sense, here, in which the mobility and communication devices mentioned in the second part of the statement, which shifts focus from clients to their families, signify their potential agency in the world, and thus serve as bastions of progress – ways to counter the stasis of disability by setting disabled subjects in motion. Yet there is also a sense in which this agency is blocked, first by the cost of equipment, and second, by the fact that families need be mentioned at all, after the initial claim to achieve the lofty goal of independence. If families rely upon Easter Seals, their mention in the second part of the statement implies that children also rely upon them, in a complex network of dependency. The suggestion, to that end, is that Easter Seals will intervene to ensure that when their work is done, no one need rely upon any service or anyone but him or herself.

I do not mean to imply here that Easter Seals has an agenda to sever ties between their disabled clients and the various support networks upon which they rely. All the same, one might consider the degree to which this insistence upon self-reliance as the organization's desired end-point locates the disabled subject's ideal state, when there is no longer "much more" for the organization to do, within classical liberal views of the autonomous subject, which, as LeFevre notes, are focused on cultivating one's inner being, isolated from others (19). One might consider, too, whether this construction does not feed into the social scientific approach to disability, whereby it is a functional problem – its status as an individual, medical condition

justifying limited state intervention, as Rioux and Valentine observe (51). If Galvin cautions against rhetoric of improving the disabled so that they may develop the self-sufficiency necessary to thrive in a consumerist economy, one might consider why here, too, the emphasis is on reforming bodies rather than problematic environments. What, then, are the implications of providing financial aid in support of an individual's pursuit of independence, and could that support then subtly pressure the individual to achieve success on the organization's terms?

Another problematic concept in this statement, which I have already addressed in brief, is the association of camp with independence. In this statement, the purpose fulfilled by sending a child to camp is left ambiguous, but Easter Seals' fact sheets, available online, make clearer the connection between this central service and the organization's chief purpose. In a bulleted list of objectives in that document, Easter Seals justifies their rationale for camp as follows. First, it is intended to "promote the development of life skills that enhance future independence." Second, it helps to "build self-esteem through activities that challenge each child's individual abilities" – emphasizing once more qualities of individuality and ability. Third, and thus lower in priority, it is meant to "provide opportunities for social interaction and building friendships." Lastly, it is to encourage children to have fun. Camp is thus the central means, along with the distribution of mobility aids, by which Easter Seals conveys its message of independence.

Again, I do not mean to suggest that the ranking of these aims marks an agenda on the organization's part to lure campers with the promise of fun, then hit them with social indoctrination and talk of becoming self-sufficient. Nor am I necessarily critical of these aims outside of this context of normalization: children perhaps ought to develop some essential skills, somewhere, if not ideally in an accessible environment. Finding their individual abilities challenged in a setting where they will supposedly not be judged for those failings might

likewise result in a valuable developmental experience, acquired, contrary to the liberal model for selfhood, alongside others. All the same, I believe it is worth asking why the focus is once again on developing “life skills” to achieve “future independence,” and why the latter is constructed as being wholly dependent upon the former. In other words, why must the disabled subject be independent, first, and why is independence framed in terms of the ability to manage on one’s own – to acquire “life skills” – and thus, though it is not explicitly stated, to achieve financial self-sufficiency? Why is independence the organization’s chief goal, leaving the fostering of acceptance to languish unexplained in that initial statement, comparatively unsupported in their programs, apart from the low ranked Speakers’ Bureau?

Barbara E. Gibson has written about this limitation in speaking of disability primarily in terms of achieving independence. If Rousseau implies that disability is a corruption of liberal ideals, Gibson, perhaps consciously targeting thinkers like him, sees it instead as a subversion of the liberal fixation on personal autonomy. Gibson attempts to find a conceptual antidote to these prevailing views that define disability as a lack by emphasizing its social constructedness rather than its allegedly natural origin. The recent “reconceptualization of disability as the product of social and material barriers rather than as a ‘condition’ to be overcome” (188), she believes, affords new opportunities for viewing the positive aspects of disability, distinct from constructions of the self’s development in isolation from the world. Gibson argues that one might examine how the relationships the disabled form among people and devices upon which they are often considered “dependent” (193) fosters a sense of connectivity, beyond what Jonathan Salem-Wiseman cites as liberalism’s “disavowal of strong constitutive attachments” (535) and “asocial conception of the person” (535). For Gibson, this view entails a “re-imagining of the contained and sovereign subject of Western discourse as fluid and *becoming*” (188).

Gibson's reframing of disability as a site of connectivity rather than corruption offers a useful alternative to Easter Seals' construction of independence. Particularly interesting, in light of the organization's framing of wheelchairs and communication devices as assistive technologies designed to unlock a given child's potential, and to facilitate his or her independence, is her assertion that assistive aids need not be seen as merely a "means to an end" (192). Neither must independence be seen as that end, except insofar as it marks the logical conclusion of the organization's services when a child reaches the age of eighteen. Independence is an attractive and perhaps a worthwhile target for a person with a disability, but it is not everything. The reality of disability, as Gibson points out, is that it calls for a life of negotiation between the person who possesses the disability and the people and assistive devices with which he or she regularly engages. Heeding Gibson's point that "selves are distributive, both confined to individual bodies and simultaneously connected, overlapping with other bodies, nature and machines" (189), this consideration of disability as a site of connectivity might thus dispel Rousseau's myth of natural equality as life endowed only with one's innate abilities, developed in isolation from others. It might demonstrate, too, that able-bodied life often calls for the same kinds of daily negotiation and interdependency, on a different scale.

This question of conceptualizing disability as a possibility rather than a limitation recurs in another perhaps problematic construction of disability in Easter Seals' policies – the person-first rhetoric that once served as their primary telethon slogan ("Kids first!") and which now appears sporadically in policy guidelines and events. The organization's main policy binder, for instance, cautions in a section on disability etiquette against referring to clients as "disabled," which implies a definitive condition; it suggests using the term "people with disabilities" instead. In a more obscure example, which intersects with the above emphasis on independence, a recent

press conference for a major corporate donation saw a member of the District Council congratulating the company for recognizing the economic potential in children with disabilities. Investing in them, he argued, ensured that this potential would one day be unlocked. The lock, if one unpacks the metaphor, is the disabled body. The key is financial aid. The natural resource is the essential self, locked behind the obscuring vestment of disability, waiting to be uncovered.

As with the organization's talk of independence, I do not mean to dismiss this rhetoric offhandedly: it is surely useful in convincing donors who might otherwise be hesitant to give to a cause that lacks any clear gains or victories, outside of improved mobility, that their investment is worthwhile. It may also be seen, along these lines, as an ethical approach to disability, insofar as it objects to discrimination on the grounds of difference, and calls for a sense of communion between able-bodied sponsors and disabled clients, imploring the former to recognize in the latter a common humanity that extends beyond their most obvious physical deviation from the ideal. The problem lies in the way that common humanity is figured as something that precedes the physical condition of disability, rendering the disabled once more as sites of intervention, subjects that may become normal, if only those layers of deviation, those unnatural appendages, are stripped away. Indeed, as Titchkowski has argued in an article on the implications of such person-first language, it may result in a way of thinking that "dismembers disability from the self" (134) by using the same logic of primacy – whereby one aspect of the self is deemed essential and the other peripheral – as in rehabilitative initiatives, except revised for charitable aims. Gibson analyzes this language of separation again with the aim of arguing for a degree of fluidity in the disabled subject, which these binary constructions of the disabled self, in reducing a complex experience of subjectivity to a simple formula, cannot possibly convey:

Even “wheelchair user” reinforces a separation that in practice cannot be sustained. The body is uncontainable...flowing into the world. Dependency as something to be avoided and independence as a goal are unproductive ambitions ... Once the connectivity of unbounded becoming-subject is revealed, the collective fantasy of the binaries of independence/dependence, self/other, disabled/ non-disabled is rendered unstable. (195)

Moreover, this separation of disability from self remains consistent with the medical model of disablement, which, as Ravi A. Malhotra summarizes, regards curing the physiological impairments of the person’s body as the quintessentially appropriate policy intervention (72).

Here, at last, one arrives at an impasse. Given the social reality of limited public funding and the fact that the liberal paradigm of thinkers like Rousseau continues to pervade western discourses on disability, does Easter Seals have a choice to promote anything other than a call for charity infused with the promise of a rehabilitated workforce, freed from the weight of disability? In other words, can one fault Easter Seals for speaking the language of capitalism – of weak disabled bodies transformed into self-sufficient, robust humans, with a little corporate sponsorship – if it is the dominant idiom of the sponsors they solicit, without whom no wheelchairs would be purchased? How, moreover, can a non-profit organization like Easter Seals raise public awareness about disability without wider systemic change?

Lest the issue be boiled down too easily to questions of finance, I will turn to a personal story not much different than the one with which I began. There is an interesting passage in Jean-Dominique Bauby’s 1996 memoir *The Diving Bell and the Butterfly* where the former *Elle* magazine editor and current wheelchair user, post-stroke, muses on the accessibility of his

surroundings. An admirer of the beach in his prior able-bodied life, he is struck, now, by the strangeness of the path required to get there – the number of parking lots, cement blocks, and other human-made objects that complicate his route. Suddenly he is conscious of the value of a good cushion, as the gravel he traverses, when wheeled by a hospital orderly, jolts his backside. He develops a new sense of what it means to go places – intensely feeling the duration of his trip, the incredible heat of being exposed to the sun for so long, for such a great distance, and the degree to which he depends on others. He realizes that this life he has found himself living requires an appreciation for the logistics of how his body must engage with various environments. If he once took it for granted that the beach was a jog away, he is now aware of the human-made barriers that span that distance, and of the time it takes to get places in an environment that seems constructed entirely to impede his progress. He is aware of the degree to which his disability exists as a compromise between his body's particular failings and the limitations of the spaces through which he now moves.

Bauby's realization, which occurs to him in a moment of wonder rather than bitterness, may be a useful model in looking for ways to overcome, paradoxically, the language of overcoming that has permeated the dominant view of disability, and isolated it as a removable appendage – a corruption of the true, the essential, the enduring self. The trouble with these observations is that I understand Easter Seals' need to maintain the view of disability as an individual hurdle to overcome rather than a limited social construction to render problematic. I understand it as I understand why the organization might also find it conducive to convince the private sector to donate in the name of "helping kids with physical disabilities succeed" by getting over their disabilities. To solicit funds on behalf of an arduous, incremental, endless, and seemingly futile process of environmental reform would surely yield less effective or at least less

financially impressive results, without at least some sense that a specific person has been improved by the effort. The difference in the individual or social pathology approach's success, relative to the other, could be marked down to a question as simple as which formulation is most likely to appeal to donors – the notion that it is the disabled individual's responsibility to transcend his or her limitations, or that it is the responsibility of the society that disables?

Indeed, given the prevailing historical forms of selfhood I have outlined, to use Bordo's term, it makes sense that Easter Seals would nominate the disabled individual for cultivation before sending society to camp. To turn a disabled reserve of potential into an independent worker offers a clear narrative progression from fundraising initiatives, to fitting a child with equipment, to success. To direct that fundraising power to reconstructing and fundamentally re-conceptualizing the environment, however, as a space where people of varying abilities can freely move without their own expensive equipment, offers no such story. Consequently, it offers little incentive to become a corporate sponsor, a one-time donor, or even a day-of volunteer. It offers no promise of a good deed met with direct benefits. In a sense, the social pathological approach to disablement is both too abstract – how might one go about addressing a disabling environment? – and too focused on seemingly minor goals to appeal to the private sector. Why build a ramp when you can “back a fighter” – a former Easter Seals slogan.

These are slogans and narratives that work. This, moreover, is rhetoric that appeals to the coffers that need appealing before offering themselves up. The question with which I am left, in light of this hurdle toward enacting the approach I see as both more ethical and practical – a ramp is concrete, but “independence” could be anything – is whether a model for disablement other than what Easter Seals has in place already may be successfully implemented in a society raised on Plato and Rousseau. Why is disability framed as a social burden at all, and how can

Easter Seals afford to frame it as anything different without alienating their financial base?

Whatever the policy documents say, the donations they receive are directed toward concrete results that render a largely inaccessible world at least partly accessible. How can critical disability theory reconcile those results with the work that remains to be done in bringing the limitations of this approach to light?

I do not mean to conclude with an apology for “independence,” the primary buzzword through which Easter Seals hopes to raise donor dollars toward the improved lives of children with physical disabilities, a goal to which the staff in Sudbury is unwaveringly committed, amidst a limited pool of funding and a glut of competing organizations targeting the same funds. I recognize both its shaky ideological foundation and the degree to which it is rooted in dangerous normative assumptions about disability as a problem to be solved. Yet I recognize its viability as a model for fundraising, given the organization’s minimal governmental support. At the same time, I see it as a necessary stage that might yet be passed through, toward a more inclusive approach to disability – one that views helping as more complicated than granting disabled subjects independence, and more involved in engaging not just with disabled bodies but also the disabling world through which they move.

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