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## Connectivity, Representation and Opportunity On-line

The web is about connecting people to information (which they may or may not need) but, increasingly, it is also about connecting people to people (which they almost always need). The purpose of personal connections can be intrinsic (social) or instrumental (sharing experiences). Often such virtual interactions and exchanges facilitate virtual relations as well, be they tenuous or lasting. Rheingold recognized early on how revolutionary these new cyber relations were going to be in his groundbreaking book on emerging "virtual communities" (1993). He was excited about the potential of these unplanned but irreversible "social experiments" in human community, but he also foresaw their challenges. In particular, he wondered if virtual communities would reproduce both the strengths and problems of face-to-face human relations; the cost and technological sophistication may even exacerbate existing exclusions. To avoid this he argued that more citizens must "contribute to the dialogue" about the web's evolution (ibid: 5-7).

## Community and Relationships

Both the websites I examine for this review aim to promote human connection through encouraging and facilitating communication, relationships and other new possibilities for people living with disability. In many ways both sites accomplish these aims well, but it is also important to address Rheingold's question about the extent to which these virtual worlds are an improvement on, or a reflection of, our pre-existing material world. In these reviews, I take access and representation to be decent proxies for people's chances for rich relational networks.

The human yearning for belonging and community is not unique to the disability community, but, for a range of reasons, rich relationships can be much harder to initiate, forge and sustain when you live with impairment (Bogdan & Taylor, 1992). The L'Arche communities were founded with, and for, people with developmental disability around Jean Vanier's core belief that mutual relationships were crucial to all of our well-being (Vanier, 1989, 1998). He rejected the socially isolating asylum experience of the 1960's as inhuman because it choked off the relational nourishment that allows humans to grow. In his philosophy, mutuality and reciprocity are not the same. Relational mutuality emerges in the flow of goodwill and caring between two people who take the time to be truly present to one another, whereas reciprocity has a more commercial connotation and implies the exchange of like-valued goods (Cushing, 2003). The latter, while more common in our society, clearly disadvantages those who have fewer socially-valued "goods" or talents to exchange.

Both of the websites that I review work against this problem through different strategies and to different degrees.

### **www.powertobe.ca**

The first site to be reviewed here is from an organization that seems nicely synchronous with Vanier's notion of mutuality, in a broad sense. The organization is Power to Be, a Canadian outdoor recreation society that aims to contribute to the growth of both strong youth and strong communities to surround them. Although they now have a variety of programs, the school was founded in 1998 specifically to promote greater access to the outdoors for those they call "exceptional youth", youth who live with impairments. Akin to Outward Bound's "Access to Adventure" programs, there are dual goals at play here: attaining hard skills in the sport, as well as the personal growth that derives from taking on new challenges.

This site should be of interest to a range of people. The primary targets are children and youth (6 to 18 years) with impairments who are interested in engaging in outdoor activities. The organization operates courses in Victoria and Vancouver, British Columbia but is not limited to people who live there. Clear information is included about bursaries available for the courses. The site would also be of interest to the families, friends and people who provide support to youth with impairment as they could be instrumental in facilitating someone's application to the program. Finally, the site clearly also targets potential donors by providing extensive information on accountability and mission. Their demographic information section indicates inclusion of people with various impairments including: cognitive, physical, learning, hearing, and visual impairments, and autism.

### **Re-Writing Representations of Impairment**

The site is organized in a relatively straightforward format with standard information options listed across the top as well as more "newsy" current items listed down the left side. To set the tone, the site opens with soft theme music about the power of doing things yourself to make the world a better place, and a short, embedded video showing

young people of varying abilities doing just that. The videos and photos include people living with a range of conditions from sight impairment to wheelchair use but the impairments are not highlighted. The organization's approach to the representation of participants' disability or disadvantage is thus understated, focusing instead on participants' satisfaction with their actions and their sense of belonging to the group and to the earth.

Rather than making a poster child or hero out of these youth, the images present them in everyday settings - as one among many people in a group engaging in outdoor educational activities in capacity-appropriate ways. In fact, after an initial scan of the site, I wondered if I had misunderstood the program's goal: Where were the impairments? A closer look however exposed that they were there, they were just not underscored. My initial response indirectly reveals how impairments are usually represented as a "master status" for people or as a barrier that must be overcome. The existence of the organization is a tacit acknowledgement that specific supports are needed for people with exceptional conditions to partake in sports like kayaking and mountain climbing. It appears however, that they have chosen not to make that the focal point, which is consonant with progressive models of representation advocated by disability studies scholars.

In writing about how disability is portrayed in various media, Riley asserts that there is usually, what he considers to be, an inappropriately overt focus on the impairment. This means that, despite the potential for changing impairment images, what is presented is effectively a distorted version of what real life with a disability is like, à la Baudrillard (2005). Riley also argues that impairment is often merely used as a symbolic tool to advance narratives of tragedy, pity or overcoming burdens that effectively reproduce stereotypical negative associations with disability. Such representations of impairment work against the badly-needed rewriting of disability scripts in the social imagination in more positive ways (Cushing, in press).

The Power to Be site in contrast, uses disability-positive language in discussing and representing the importance of providing the supports that are needed in order to realize social inclusion in the

community as a reality and not just as a theoretical possibility that comes with rights. The site also invites all community members to participate in the program in various ways and the images suggest that this is an inclusive approach that aims to build “positive social circles,” confidence, and social skills for students.

### Room to Grow

If there are issues with the site, they are in the area of accessibility and detail. On the positive side, the site is uncluttered and makes good use of photos and images for those who do not read. Still, given that a primary target group for the organization is people with impairment, and specifically, with cognitive disability, greater use of simple symbols alongside sections and titles, and greater use of plain language as advocated by the AFC (2008), would significantly widen access. Access would also be enhanced with an audio option for verbal description of the videos and photos for those with sight impairments.

In keeping with their goal of encouraging youth with impairment to choose to engage in the outdoors, it would be helpful to have a section where past participants with impairment discuss in more detail how their engagement was facilitated, what was challenging, what proved much easier than anticipated, and so forth. While there are already interesting testimonies about what past participants enjoyed and how they grew, there is little impairment-specific discussion of how one’s participation, as a person with a particular impairment, might be facilitated. Having worked in this field and seen the common anxieties of all youth considering the new risks of a mountaineering or white water course, it seems reasonable to assume that these youth will share these worries plus additional concerns about the quality or character of impairment accommodation. Impairment-specific stories of the experience and adaptations just might help to quell a potential tripper’s trepidation enough to make the phone call.

### www.disaboom.com

Disaboom is another site that promotes human connection and a combination of goals that bear discussion here. This site went live in October, 2007, and combines health and practical information with opportunities to share your own story and connect with others in a variety of ways. It is a creative attempt to incorporate what is helpful about the medical-functional approaches to impairment without allowing them to dominate. A balance is achieved through also providing diverse perspectives and sections that are more consistent with the social-environmental-rights models of disability. The site content is updated with impressive regularity, showcasing a steady turnover of thoughtful feature articles across a spectrum of topics.

### Site History and Philosophy

In the “About Us” section, Disaboom describes its mission as being: “to create the first comprehensive, evolving source of information, insight, and personal engagement for the disability community.” The founder, Dr. Glen House, notes that living with quadriplegia and training as a doctor have given him “firsthand knowledge of the challenges faced by individuals with disabilities and those whose lives they touch.” This inspired him to create this kind of resource. By that definition, the site will have relevance for all kinds of people who count themselves part of this expansive group. The site and all features are free for users owing to the owners’ successful pursuit of site advertising revenue. I chose to review this site for two reasons: first, because the high-quality of information and diverse areas of coverage make it a valuable resource for the disability community (including family and support people). Second, I believe the site content, and what is missing from the content, raise some important questions about the real barriers to creating a truly inclusive virtual community.

The core beliefs of Disaboom reverberate with a decidedly upbeat and hopeful tenor and echo principles of the inclusion approach in valuing diverse stakeholders’ concerns and diverse kinds of knowledge, and by targeting the whole disability community. The four core beliefs are paraphrased below:

1. Expertise comes in many forms: professionals and peers
2. Knowledge is power that can be enriched through community-building
3. All are touched by disability: the site includes a diverse membership
4. Disability does not define us: we decide who we are

Points two and four reflect a belief in the power of political action through working together to promote certain goals, but also through resisting the negative, limiting stereotypes commonly associated with having a disability. Indeed, a recent article about the site cited the founder as saying that “The boom in disaboom is about blowing up the previous perceptions of what a disability means” (Krueger 2008), suggesting a desire to work towards positive new scripts. Various aspects of the site clearly contribute to this remit: the dynamic, contemporary feel that the site has; the many stories of athletic and career success being enjoyed by people with all kinds of impairments; the colorful photos; and most importantly, the content of the articles.

### Relevant and Problematic Content

A key feature of the site is a jump-linked menu of “conditions” ; when you choose one, it takes you to condition-specific pages. Each condition has some common format elements and some customized ones. For instance, each has three common tabs - Summary, Core Knowledge, and Articles - under which you find extensive, but not overwhelming, information about the condition, its history, diagnosis, effects, and treatment as well as all articles relevant to this condition on the Disaboom site. This tool is much simpler and more accurate than typical “site search” functions, which always seem to find everything but what you actually searched for. This section is intrinsically embedded within a medical/ functional model schematic, but this kind of information is often precisely what people want, especially, for instance, in the face of a new diagnosis for self or for a parent, child, or partner. The style is not too entrenched in medical ease however, sometimes the implications are problematic. For instance in the discussion of Cerebral Palsy (CP), the summary states, “a diagnosis of cerebral palsy is one that frightens parents.” My concern is not so much that this is a false statement (some parents certainly are

frightened), however, not all are, and there is no mention of other kinds of responses. Moreover, much of the rest of the discussion seems to focus on assuring parents that most of the conditions won’t apply in their case, or can be overcome with appropriate intervention.

While I do not deny that many parents might be looking for exactly this kind of reassurance, the discussion was disappointingly unfettered by progressive ideas from the social model of disability that could provide a necessary balance to the interventionist approach. This kind of paradoxical “good news” / “bad news” user experience was common for me while exploring the site. There are dozens of features with good quality information, but they are often imbued with an ethos that implies or explicitly reproduces an individualized, pathologized understanding of impairment. It would behoove Disaboom to attend more to the conceptual advances of disability scholars such as Lennard Davis who have worked against these tendencies in imagining and representing disability (1997).

This is not a straightforward case however, given that, in general, the site is facilitating diverse options, possibilities, and positive messages about life with impairment. There are, for instance, a number of journalistic articles designed to move beyond the typical media fare; these are often written exclusively for the site. “Dating and Relationships” within the “Lifestyle” tab includes several articles that overcome the common taboo on discussing sexuality in the same breath as disability. “Can Disabled be Sexy?” serves up antidotes to seven common, negative myths about sex and disability that would be familiar to people in the field but would be a helpful eye-opener for people with a new condition or a new friend with an impairment. “Becoming Your Own Sex Advocate” addresses both practical and political means of improving individual sexual-medical support. Other topics include sharing “embarrassing things” with a new lover, or getting out of abusive relationships. Content such as this naturalizes the sex-disability link and helps to work against stereotypes just as the social model of disability aims to do.

### Success

Disaboom is clearly doing something right. After just 6 months of being live, their Shareholder

letter (April, 2008) claimed they had 2.5 million visits, 9.3 million page views, 23 million ads and over 42,000 “registered and engaged users” who have posted an entry or comment. Third quarter results (posted October, 2008) indicate continued growth with a 50% jump in the number of unique monthly visitors in September versus August, 2008 and 90% organic site traffic (i.e., from unpaid listings in search engines or directories). Without a comprehensive examination of this vast site, it is difficult to fully assess where this engagement is happening, but comment activity is uneven across the site with a number of feature articles and blogs having just one or two comments. Perhaps this is simply a function of the “newness” of the medium, as people are taking their time to figure out where and how they can participate, but it may also reflect the nature of some of the content.

Some articles and blogs did, however, have a number of entries. One such article, by an in-house writer, Cheryl Petso, exemplifies the possibilities of this website. Petso’s article blended day-in-the-life vignettes of Kelly and her twin, teen boys with cerebral palsy, with snippets of wisdom that she had earned through her fights for supports for her boys and other families in her job at Family Voices. The article captured both the intimacy of personal experience and more general helpful insights such as when the upbeat and resourceful Kelly gives tips for breaking down relational barriers in public, and advises parents to both “hope for the best, and prepare for the worst” (conceding that difficulties have not vanished for her family in spite of having achieved various supports) (Petso, 2008). It is a great example of Disaboom’s goal of facilitating peer-to-peer information sharing, and reader’s appreciation for this type of content is evident in the extensive comments listed.

### The Paradox of Competence

Part of the appeal of Petso’s piece was the very regular nature of the mom, Kelly, and the struggles of her boys with common challenges associated with cerebral palsy. Several other articles on the site take a different tack, focusing on the exceptional accomplishments of a few exceptional people. For instance, two of the four feature articles for the second week of October, 2008 were about elite para-Olympians and the heights they had reached, while a third

showcased luxury bathrooms in discussing adaptive equipment innovations. A lead article under “Arts” was about a world famous opera singer who also lived with the physical anomalies common to thalidomide poisoning. These articles clearly aim to dismantle negative images of people with impairments as being passive under-achievers with no social contribution to make; an admirable representational project. There is however, the knotty issue of the subtext of a person’s value being hand-cuffed to compulsory competence or even super-competence.

Indeed, the whole argument of one popular blog entry consisted of enumerating several high-achieving “crips” in order to disprove an ignorant comment by a U.S columnist that people with Down Syndrome are “marginally productive (if at all)” and should be aborted (Disabled Politico 2008). As evidence of the wrong-headedness of the columnist, the blogger cites a number of examples of people with cognitive impairment who are accomplished contributors. I do not deny that holding up such performers is one way of working against recalcitrant negative stereotypes about people with disabilities. The use of this strategy however, begs the question of how it will affect the perceived “under-performers”: in other words, how then does one defend, or stand by, those whose impairment precludes them from “contributing” in any traditional sense of that term?

In his historical look at Ontario’s asylums for people with disabilities, Simmons highlights the danger hidden within every bureaucratic claim to achieve rehabilitation: those least able to contribute or develop productive capacity are the most likely to be excluded altogether or denied vital supports (1982). The results-driven asylum administrators saw this group of people simply as a waste of rehabilitative resources that could be put to better use with those who were deemed more “trainable” (loc cit). Today, the preference utilitarian arguments for infanticide and selective abortion follow a similar logic: that in the sand of contributions, there is a line that we can draw, below which it is acceptable to terminate the “offender’s” life. To be clear, Disaboom, in no way, explicitly uses this logic, and I do not want to imply that. Yet the competence-subtext surfaces frequently in the site. Furthermore it is also concerning that the site has so little inclusion of congenital developmental and cognitive

disability conditions.

### Missing Persons

The website's "list of conditions" menu has no link for any variation of the general category of "intellectual disability" nor any for common specific conditions like Down syndrome or Autism Spectrum Disorders. There are conditions listed that can include neurological impairments (e.g., CP, MS, ALS) but these are not principally an intellectual disability in the main sense of that category, and intellectual impairment often only appears at advanced stages of these conditions. I emailed Disaboom twice about this conspicuous absence and two different responders indicated that there was no intention to exclude people with intellectual disabilities and that new conditions are added as people blog about them, which they recommended I do. While no one expected Rome to be built in a day, there are four concerns raised by Disaboom's response, concerns that are especially noteworthy for an otherwise thorough site.

First, this site has been live for a full year and boasts a vast membership of which, surely, some members are touched by intellectual disability. Second, I found a user inquiry with the same question a year ago that received the same answer I did (PollyB, 2007). Third, far less common conditions are already represented. For example: ALS (U.S. prevalence, 0.001%), and ankylosing spondylitis (U.S. prevalence, 0.25%). Given that 2.5 to 3% of the population of Canada and the U.S.A live with intellectual disability (depending on definition), it seems reasonable to expect to find on the site at least a general section for this condition and not merely occasional individual articles.

Perhaps the most troublesome point, was the Disaboom respondents' suggestion that conditions will be represented as they are blogged about. Although I accept that, typically, a user-driven site will reflect the activity and demands of its users, in the case of a site that aims to be pan-disability, and is only partially user-driven, this laissez-faire dog does not hunt. Some impairment conditions clearly present significant barriers to people with those conditions in their ability to contributing content to the site and/or make the needs known on their own. Not to mention that the allies of people with intellectual

and developmental impairments are famously overworked and underpaid, making them unlikely co-bloggers. This conundrum is not limited to Disaboom; a general problem with new media is that people with developmental disability and their allies continue to have limited capacity or opportunity to produce and upload meaningful content on many sites. We need more discussion on how "plain language" or symbol use could be better incorporated into such sites without subtracting from other users' enjoyment (ACF 2008). Is there perhaps a fear that a more explicit inclusion of intellectual disability would detract from the attempt at disassociating disability from deficits?

### Ethos Effects

The Disaboom motto is to "live forward" and founder Dr. Glen House says this means to live your life with an eye to the possibilities that the future holds. House acquired impairment when he was 20 years old and says he "never allowed the accident to become a life-stopping event" (Krueger, 2008). This ethos infuses the site in ways that are both positive and problematic in terms of disability representation. As I have already written, many articles profile people who are living full, successful lives alongside the challenges that impairment presents. These stories give the site an energy and optimism that creates an overall impression of disability being naturally associated with hopefulness and the power of possibility. Lead articles in other weeks have covered topics from accessible vacation spots and gardens, tips for amateur athletes, and other everyday human interest stories. The excellent site design and the high-calibre sponsors associated with, and advertising on, Disaboom are also striking. Portraying people with disability as consumers with buying power is, in some ways, an important move away from stereotypical associations of disability with unavoidable poverty and social and consumer irrelevance. Positive scripts of people living with impairment are sorely needed, as Riley has written (2005). In this sense, the site is serving the disability movement well.

What is problematic about this ethos is that it walks a very fine line between shining light on how people are unlocking the pleasures and productive potential of life with disability, and reproducing the same old deficit-performance

logic that sees impairment as merely a barrier and that ties individual value to capacity. Michel Desjardins calls this the “Sisyphian task” that has long burdened people with intellectual impairments (2000). It is precisely such instrumentalist logic that Jean Vanier writes against. Since the late 1960’s, he has consistently emphasized that imperfection, fragility, suffering, and interdependence are experienced by all humans (albeit in varying degrees): they are not the exclusive domain of those with cognitive disability in spite of what those who seek to exclude them claim (1989; 1998). He insists that only when we can honestly admit that these are more salient common denominators of human experience than the obligatory normalcy we vainly seek, can we effectively imagine people with even profound cognitive disability as members of the regular spectrum of human variation, rather than as a distinct, and less-valued category of people as they often are now.

The bottom line is that alongside the many positives of this website, there is an overemphasis on people in the “top tier” that unfortunately hints at the awkward, hierarchical effect that often emerges when any group tries to lift itself away from stigma. In addition to stories of excellence, competence, and overcoming one’s impairment, Disaboom should try to expand its narrative repertoire to include the more humble themes of valuing simple presence and life-sharing, coping in ways that are more mortal than heroic, and strategies for coming to peace with what is, without discounting what could be.

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