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## Media and Messages: Exploring Old and New Worlds of Developmental Disability and the Media

### Reflecting on Media and Developmental Disability

Since the Journal on Developmental Disability began publishing in 1991, media reviews have been part of its offerings. Among the first were reviews of non-fiction books, with a strong emphasis on clinical and academic materials. By the mid-1990s, however, the scope broadened. Hollywood films, *Dumb and Dumber*, *Nell*, *Forest Gump* and biographical works such as *Still Life with June* were reviewed. The intent of these was to challenge the limited and negative portrayals of people with developmental disabilities and, more rarely, to celebrate imagery and ideas that eroded worn stereotypes.

In more recent years, reviews of websites and internet-based resources appeared, reflecting the introduction of new media forms. These reviews were tentative, focusing mostly on the Internet as a neutral source of information, intended primarily for family members or service providers. But then, the Internet and computer mediated communication was still relatively new. When the first website review was published in the Journal, only 60% of non-disabled Canadians had a personal computer (Statistics Canada, 2003, p. 95). From this context, the opportunities to attract contributions based on new forms of communication were limited.

Over the past 17 years, digital, computer mediated communication and media forms have proliferated. Despite dire predictions that these would replace older, mainstream forms, new media has not dominated, let alone displaced old media (Rossetto, 2008). Instead the array of possibilities for what counts as media has diversified. Print, artworks, television and film – generally defined as “old media” – share the communication terrain with its new digitized counterparts: Internet, YouTube, live-streaming, gaming, podcasts, text messages and so forth.

As media forms have expanded, so too have the possibilities for thinking about disability. Technology and societies are mutually constitutive, and as such, new media carries implications for the messages we can transmit about disability, as well as who can produce, process and receive those messages. However, technologies are too often assumed to be inherently good or value neutral (Goggin & Newell, 2004), and are assumed to “naturally” improve the lives of disabled people. As disability and technology scholars Gerard Goggin and Christopher Newell (2006, p. 310) point out, “...our taken-for granted technologies can be enabling

or disabling according to the norms that are built into technological systems". In this column we hope to critically examine the power relations influencing and inherent in new media, while we remain open to the social forms it engenders.

### Call to Contributors

Thinking about how new media pushes, extends, transforms or even constrains and entrenches the representation of, and conditions for, people with developmental disabilities remains largely unexplored. Future contributors to the column can grapple with the implications arising from the advent of new media. Below we've sketched possible areas of exploration and reflection.

## New Media and Innovating Language

New media holds great promise for people with developmental disabilities since innovations in digital technology allow us to combine multiple media forms, making communication more flexible and dynamic. For instance a website can contain written and spoken text, photographs, video or other visual imagery, music, running blogs, interactive and collaborative wikis, links to other websites or podcasts and on and on. As communication becomes more complex, symbols, images, sound and text work together to create new meanings and messages of disability. The BBC Ouch website is a good case in point; the site editors regularly critique stereotypes of disability through juxtaposition and humour (<http://www.bbc.co.uk/ouch/>). For instance, podcast hosts Matt Fraser and Liz Carr take up the deeply derogatory practice of referring to disabled people as "vegetables" (Carr, 2008). They subvert the popular trivia game "animal, vegetable or mineral" into a disability version: "vegetable, vegetable or vegetable". In order to be hurtful, a slur – like vegetable – relies on everyone understanding its meaning similarly. However, Fraser and Carr layer the word "vegetable" with other words, images and humour placing it in a new interpretive context. Some may come away from the website with the disparaging meaning of the word vegetable intact (always a risk). However most of us may find that its underlying ableism is exposed, allowing us to attach new subversive meanings to the word. Like *crip* or *gimp*, the word is re-claimed through wit and

a little cheekiness. The Ouch website relies on placing stereotypical language or images in a rich media context, so that visitors encounter many competing ideas at once to interpret the image in new and transgressive ways. The stereotypical and derogatory meanings of the words or images may be dismantled without ever articulating a direct critique.

New media may also provide novel ways to express the experience of disability, allowing for engagement across physical, sensory and cognitive diversities, rather than merely reproducing simple categories of difference. Communicating through multiple media forms might allow us to disseminate messages that depend less on wholeness, integrity, continuity or coherence. New media forms may be particularly effective at challenging normative representations of development and social interaction. For example, text and instant messaging rely less heavily on complex imagery, full narratives, vocabulary and grammatical mastery than letters or even telephone conversations. Terse, concise statements replace longer explanations and single letters replace full words. At a practical level, this "stripped-down" form of communication offers opportunities to people with developmental disabilities who may have found the literary demands of traditional prose a barrier to communication. At a symbolic level, the greater reliance on fragmented and intermittent forms of communication will change what counts as "articulate" and coherent – possibly creating social spaces for people with developmental disabilities to represent themselves.

### Call to Contributors

Future reviews could take up the question of how a specific work creates new language and new understandings of developmental disability. Potential contributors could examine how the work in question directs and expands our understanding of developmental disability through the creation and reorganization of symbols and meanings. Reviewers also might consider how a work erodes myths and anachronistic ideas about developmental difference through challenging taken-for-granted meanings of language.

## New Media and Social Networking

New forms of media open up new possibilities for communication for all involved. New media is more interactive than ever, yet doesn't rely heavily on face-to-face or embodied interaction as in traditional forms of communication. Disabled people have found themselves judged and marginalized based upon their failure to meet embodied norms. Even in telephone calls which have not relied on face-to-face contact, "the body" and mind can be apprehended. Tone of voice, speed and pacing of speech, oral pitch, articulation and aural processing are some of the ways impairment is evident over the telephone. Body gesture and comportment, which has been integral to the age of television and film, takes on minimal or no significance on the Internet. This has created new space for people with developmental disabilities to interact with the broader community. People with developmental disabilities, previously believed to "live in a world of their own", have creatively grabbed onto a full array of new media technologies to smash stereotypes and form social connections not previously believed possible. For instance, in the virtual world Second Life, a new digital community, *auttie world*, has emerged. Neurodiverse people and their allies can assume a three dimensional computer image – an avatar – and interact with one another over the Internet. Members of "*auttie world*" can form friendships, educate one another, engage in romantic liaisons, organize politically or share resources without the stigma and stress that may come with immediate "real world" interaction.

While people with autism can use digital communities to form social networks and create a sense of cultural identity and self-expression, new dilemmas arise. Computer-mediated interaction may displace embodied personal contact. Electronic forms of interaction may be used as a way to cover over continued physical and social segregation and isolation. Not unlike the critiques leveled at day programs that allow participants to sit in front of the television for hours (Parr, 2007), online interaction can be assessed as a convenient, yet insufficient substitute for social interaction.

## Call to Contributors

Future reviews could seek to identify possibilities for social networking. Does the reviewed work open up or constrain these possibilities? Where face-to-face interactions have left people vulnerable to stigma, computer mediated communication may offer some protections. Are any protections offered through the reviewed work?

## New Media and Social Organizing

New media can take social networking beyond individual interaction to create and organize transnational and global "virtual communities". Building solidarity around common issues by digitally disseminating counter-hegemonic photographs, videos, stories and other message forms have created new opportunities for political action and organizing. The Battle of Seattle, the abuse of inmates in Abu Ghraib prison and the protests by Buddhist monks in Tibet have all used digital technology – even cell phones – to transmit images "from the street" to raise awareness of exclusion and oppression. Similarly, the disability rights community has used the internet to share concerns and protest the violent treatment of people with disabilities (e.g. Dick Sobsey's ICAD listserve, <http://www.ualberta.ca/~jpdasddc/abuse/ICAD/ICAD-faq.html> and Not Dead Yet, <http://notdeadyetnewscommentary.blogspot.com/>) and generally raise concerns about disabled people's circumstances. While there's a growing acceptance that new media has a significant role to play in building solidarity among marginalized people, we still struggle to find many concrete models for people with developmental disabilities. Even online organizing by established disability rights advocates who may not have the lived experience of developmental disability.

## Call to Contributors

Future contributors can identify the opportunities for forging alliances, education and other forms of political organizing that lie ahead for people with developmental disabilities and their families. We encourage reviewers to consider how the reviewed "media" facilitates social and material change in the lives of people with developmental

disabilities and their families.

Although the expansion and diversification of media may lead to democratizing changes for people with developmental disabilities, the Internet and other forms of new media communication may simply result in their continued exclusion. In theory, new media, online publication and computer mediated communication are consistent with the aims of self-advocacy, since people should be able to control the expression and dissemination of their own concerns. Unfortunately studies of computer and Internet use of people with developmental disabilities suggest that people are not consistently enabled to take advantage of the organizing features of new media (Seale, 2007).

### Call to Contributors

The democratizing promise of new media lies in its capacity to promote concepts that disrupt the official and authoritative narratives of “the truth” of developmental disability. Mass media “products constitute an important mode of discourse by which the culture perpetuates itself and its perspectives...” (Norden, 1994, p. 3). Online publication allows everyone from elite to grassroots producers to contribute to the construction of these discourses (Dean, 2003). Sites produced by advocates, family members, service providers, clinicians, religious communities, and people with developmental disabilities put forward competing portrayals and messages of developmental disability. Future contributors to the column can explore whether the media under review offers a dissenting account of developmental disability, one that promotes alternate understandings. By the same token, reviewers should consider if the work reproduces old misrepresentations and social divisions. Misrepresentation of disability serves as a powerful tool in the oppression of disabled people. Indeed, visual and literary misrepresentations of disability are often the only, or most important, space where non-disabled people come to know disability and its perceived place in the social world (Abbas, Church, Frazier, & Panitch, 2004). Contributors must ask if the reviewed work perpetuates old misconceptions and stereotypes of developmental disability. Is new media simply one more site for enacting disability oppression?

## Complicating Questions of Accessibility

Ensuring that disabled people have access to all media forms, including computer mediated communication, is imperative. No one wants to be left behind in the digital age. As technology develops, we can anticipate the widening of the digital divide - the gap between those who use computers and those who do not (Dobrinsky & Hargittall, 2006). Social divisions may be further deepened by the digital content divide: the degree to which people can exercise flexible choice in what they access online. The digital content “haves” may access interactive non-linear forms of media (e.g. on-demand information such as tivo, web-surfing, facebook, chat rooms, blogs) while the “have nots” continue to passively consume traditional linear media, (e.g. television, radio or advertisements before a movie screening) (Mercado-Kierkegaard, 2006). Due in part to inequalities in age, education, income, race and employment (National Telecommunications International Administration, 2000: 67-87) disabled people are about half as likely to own a personal computer or to have consistent access to the Internet as non-disabled people (Looker & Thiessen, 2003). The consequences of these inequities are especially profound for people with intellectual disabilities, since access to computers, the Internet and other forms of digital media is essential for inclusion in the knowledge-based economy. Normative standards of knowledge remain one of the greatest barriers for full participation for people with intellectual disabilities, a situation that can only be worsened through their disadvantaged location in the digital divide.

### Call to Contributors

Future contributors may explore whether new media forms give rise to new divisions among people: “the haves and have nots” of technology. Reviews should explore if people with developmental disabilities can access new technology. (Do they have the money? The literacy? The numeracy?) What access features exist for people with developmental disabilities? How do we get a hold of these features? What access features need to be developed and who will take responsibility for their development? Whose values and interests will prevail as we try to remove barriers to new media communication?

This brings us to a second dilemma around accessibility. Access to information does not translate into the opportunity to use that information in a meaningful way. New media is text-intensive and therefore reading takes on new importance (Shirky, 2008). Text now appears in what was once predominantly visual media; with media convergence, text now appears in television programs, photographs, music and movies. To complicate matters further, books and other old print media are increasingly available in digital formats. To access these texts we must navigate unfamiliar and sometimes confusing instructions. Digital information is now transferred between technologies. We're compelled to access information through small, difficult to read devices, such as iPods, Blackberrys or cell phones. All of these changes present new barriers to information access for people with developmental disabilities. In this issue, a group of youth with developmental disabilities describe their experience of attending a textually dense museum exhibit. At the exhibit, the youth were faced with large panels of print narratives and descriptions, too difficult to penetrate without significant support. Although the curators had provided print alternatives by making podcasts available, the youth found the instructions for downloading the podcast almost impossible to understand. Youth had information, but couldn't access it meaningfully. Their review describes how their support workers 'translated' the exhibit.

### Call to Contributors

Future contributors should consider how people can be supported to access and evaluate the media under review. Who will teach disabled people to access media (new or otherwise)? Who will show and explain the different types of media and how to use them and how will that happen?

The review described above raises a significant dilemma which potential contributors might consider. What would have happened if the content of the information didn't meet with the approval of support providers? What happens when the information sought is of such an intimate nature, that people with developmental disabilities and their allies feel they can't easily reach out for support? Future reviews may explore the degree to which new media inadvertently creates new dependencies.

### Questions of Vulnerability

Knowledge of new media, the worlds it allows us to access, and the social networks and contacts we can make in those places are important forms of social capital. Yet paradoxically, as people with developmental disabilities open themselves up to the world of computers, technology, gaming and so forth, they are subjected to new forms of critical scrutiny, surveillance and vulnerability.

One manifestation of this dilemma is the belief that computer mediated communication poses unique dangers for people with developmental disabilities. People with developmental disabilities are viewed as at-risk of identity theft, cyber-bullying, financial fraud and other online abuses – however it is difficult to know whether these risks are any greater than for the general population (Seale, 2007). It's also difficult to safeguard against these risks without individualizing the responsibility of safety. Users of the Internet are exhorted to proceed cautiously, refrain from sharing personal information, assume anonymity, keep networks small and otherwise modify their online practices.

Few formal institutional policies exist to safeguard against Internet and new media abuses (Mercado-Kierkegaard, 2006). The few that exist are directed at the protection of children. Care providers are encouraged to supervise, monitor and ultimately control young people's online/digital activities. As the only substantial model for new media safety, guidelines designed for minors may inadvertently structure the supports offered by service and care providers to those with developmental disabilities. People with disabilities may find computer mediated communication another arena for infantilization. They may lack the privacy and freedom of other adult users.

A second problem arises when the online actions of people with developmental disabilities come under undue scrutiny. Recently, computer-based activities have come under critical examination. Researchers, social commentators and policy makers have decried new media for making our population "lazy and stupid" (e.g. Carr, 2008). For instance Nick Carr despairs over the loss of deep reading – reading accompanied by reflection, critique and response; while people

may be reading more than ever, our engagement is superficial. Like the criticisms of the “idiot-box” (or television) during the 1980s and 1990s, computers and other digital technologies are blamed for eroding our intellect and sociability. To fully appreciate the problems this bears for people with developmental disabilities, it is important to recognize that media can be a re-embedding social mechanism. It (re)constructs and institutionalizes patterns of interaction; social relations are reproduced including disability relations. If new media are seen as turning us into automatons, satisfied for the quick, shallow information fix from a Google search or the intense solitary engagement with a gameboy, then people with developmental disabilities are particularly vulnerable to characterizations as passive consumers. Without supported access to producing and uploading information on the Internet or through any other new media modality, people with developmental disabilities will have little presence in the digital community. They will remain forced to observe, but not actively participate in the virtual world; they will find themselves stuck in familiar and demeaning social locations.

### Conclusion: A Call for Contributors

We’re calling on contributors to take up the challenge of reviewing media, in all its forms, with an eye to the opportunities and pitfalls inherent in the broader “vamped-up” terrain of communication.

We’re seeking a range of contributors who are willing to grapple with the questions coming out of our contemporary communicative environment. We welcome traditional critical considerations of how a play, art exhibition, movie, website or blog takes up, constructs or informs developmental disability. But, we also encourage submissions that don’t adhere to the conventions of journal reviews. Consider submitting transcribed conversations, hybrid texts (perhaps a text with a video component), photo-narratives, drawings or reflective pieces. We believe that by multiplying the ways in which we communicate, we can generate more insights and expand on who can voice them. Contributors should avail themselves of the opportunities to combine different forms of writing and media content.

We welcome academic contributions, but we’re hoping for a diversity of voices. We want to hear from people with developmental disabilities, their families and peers, service providers, students ... or any combination of these in dialogue. In this issue we include a review of *Out From Under: Disability, History and Things to Remember*, exhibited in the spring and summer 2008 at the Royal Ontario Museum and slated to appear in other North American venues. The review is a dialogue among teenaged consumers of an organization serving people with developmental disabilities. Morgan Ineson reviews *Autism the Musical*, drawing also on responses from audience members at the 2008 Community Living Conference in Toronto. Finally, Pamela Cushing reviews two websites, *The Power To Be and Disaboom*. The three reviews cover widely ranging media forms, and suggest enduring problems of public voice and media access for people with developmental disabilities. Yet all three point to the new and potentially empowering messages of disability.

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