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Interview with Ray Cohen, Founder of the Canadian Abilities Foundation

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In May 2010 I interviewed the editor of Canada's first and only disability-themed magazine, *Abilities*. The interview was one of five interviews conducted in an attempt to understand how and why journalists produce disability-based stories as they do. We sat in his grey-carpeted office in downtown Toronto, a few floors above commuters ringing bike bells and honking car horns on College Avenue. As journalists, we knew this interview was an odd one framed by scholarly rather than journalistic procedure — semi-structured, opening with an informed consent form, and concluding with written instructions to publish his name rather than remain anonymous as per the funder's policies. Clashes between journalism and critical disability studies punctuated our conversation as we tried to navigate our positioning: was he a journalist or an advocate? Was I a researcher or a journalist? Nevertheless, Raymond Cohen, who asked me to call him Ray, spoke for over an hour about his career as the CEO and founder of the Canadian Abilities Foundation and why he ran *Abilities* as he did: attempting to be inspirational despite editorial and scholarly critique of his methods, thinking his work impacted the public only vaguely, and sniffing out a good disability-based story only to face barriers telling it. And, of course, hoping the magazine could make it through an uncertain future.

On March 22 of this year Cohen died suddenly. I had not seen him in person since that interview, though we spoke using Skype from time to time. I took him to be a warm, friendly person, and, unknowingly, I emailed him on the day he died to arrange an in-person chat over coffee I had, of course, put off for too long.

I did not know Cohen well enough to offer the touching tributes others have offered online and in person. Instead, I can say with some authority that Cohen's work represents a chapter of journalistic disability activism in Canada and therefore his career is worth our pause. His work also offered a venue for journalists like me who are hungry to bite into disability narratives mainstream press can't always stomach.

I have trimmed and lightly edited the 2010 interview here with hopes that readers might come to better understand the motivations of a person whose ideas of how disability should be communicated created a niche for disability-related journalism in this country, therefore leading the way in merging journalism and disability, however tumultuously. The questions I asked Cohen in 2010 are not necessarily questions I would repeat if I could interview him again today; perhaps he would say the same of his answers. Nevertheless, Cohen has invariably left his mark on the ever-evolving scene of journalistic, disability-related storytelling in Canada. Here is a brief fragment of his story to be added to our history of disability.

CHELSEA TEMPLE JONES: Why did you start *Abilities*?

RAY COHEN: Well my last job prior to 1986 was at Alberta Children's Hospital in Calgary. My job there was to start the department of childcare, which existed within a school in the hospital setting. And in order to go to the school you required at least three of the therapies that the hospital had to offer. So in other words these were kids with disabilities with high needs. [When] these kids reached the age of eighteen … [they] had to leave school. For them it was like falling off a cliff in the sense that they were, for most of their lives — all of their lives in some instances — involved in a heavily resourced, wonderful environment, as children's hospitals tend to be.

Then all of a sudden they hit the magic age of eighteen and they're out of there, into the world of being young adults in not nearly as pretty a situation.

So, at the time I was also leading a support group for the parents. And I noticed that they were becoming more and more anxious as their kids started to get closer and closer to the age where they'd have to leave. So that's why I made it my business to go out there and find information, inspiration and opportunity for these kids. I began to realize that this wasn't a Calgary specific phenomenon. This is actually a national and international issue where the world of disability can be a very bleak place in the absence of information, inspiration and opportunity. And so I became a little bit obsessed about trying to share that information as widely as possible.

So I walked into the office of a publisher named Flemming Nielsen who had been publishing a magazine called *City Scope* in Calgary and told him about my idea, and he loved it and mentored me into becoming a magazine publisher, and that's how *Abilities* was born. We created a non-profit structure because neither one of us had the money to start a magazine, but we managed to start this charity and went to a local service club to get the first money, sold enough advertising to put out a second issue, and grew it from there. And it's been hand to mouth ever since, basically.

CTJ: Can you describe the challenges versus the benefits of your job today?

RC: The challenge is, as with most non-profit organizations, we're under resourced. What I mean is that we don't have core funding so we're constantly in need of raising more money. Thus has it been since 1986 and I don't expect that to change anytime soon. Somehow we've managed to put out 82 issues of the magazine in that time. That's probably the most stressful part of the job. The benefits are manifold; every three months we get to discover all sorts of new information we get to share with others. And core to the function of *Abilities* is to provide information, and to make that information inspirational and give people the opportunities to participate in things that they come across through us that they'd like to pursue. And that is what makes my world go round. I really enjoy that. I would say that that's the biggest benefit to the job.

CTJ: You say, "we." How many people are behind *Abilities* magazine? I think you could look at the publication like this and imagine a newsroom buzzing with people.

RC: So here there's three people involved on a full time basis, myself included. And then there's part time pre-press person, and a part time art director, and of course a part time printer. And then a whole network of people across the country who write for the magazine.

CTJ: When it comes to the work of the people at *Abilities*, what would you say the general attitude is in this publication towards disability?

RC: I think there's a great deal of sensitivity. We're careful to pick and choose our words carefully. We don't talk about disabled people; we talk about people with disabilities. There's a qualitative difference. We don't talk about people being confined to a wheelchair; we talk about people who use wheelchairs. In general the spin that we put on disability is not advocacy orientated. It's more positive in the sense that there are organizations out there doing good advocacy work and we like to support them, but we're more concerned with the aesthetics of life. So we'll do things like travel and fashion, innovations, things that that give colour and texture to life whether you have a disability or not, and we try to make it accessible to people with disabilities.

CTJ: Can you talk about your own attitude towards disability and how it's been shaped throughout the years?

RC: It's been a learning process for me. The magazine's first name was *Abilities: Canada's Lifestyle Magazine of the Disabled* and I realized before too long that that wasn't too political savvy to say "the disabled" because people with disabilities are not "the disabled" — it's not an ethnic group. So we've changed that to its current name.

And I got to be more knowledge about the range of disabilities through association, through meeting people, and through learning about different kinds of issues and realizing that disability is not a homogenous group. It's not as though everyone who has a disability knows everyone else with a disability. In fact within disability groups everybody's an individual and, for example, a paraplegic doesn't necessarily relate to a person with an intellectual disability just because they both have disabilities. And the same is true in the broader context of society as well.

I've also come to realize that the stereotypes of people with disabilities as either being extremely cute because — ah, look at that nice kid in a wheelchair. Or superheroes — look at Rick Hansen, he can wheel around the world. But it's not so. In the world of disability you've got the same range of geniuses and turkeys that you have within the mainstream.

CTJ: Would you comment on how you choose the language you use when journalistically referring to disability?

RC: Sure. The language is important is because I think the language molds attitude. If you think back, for example, to the Tracy Latimer situation, Tracy Latimer was a young girl who was killed by her father because of her disability [in 1993]. And it was regarded very much as euthanasia, as mercy killing, by much of society. In fact it was an issue that I feel divided our country, few people were willing to call that murder even though I believe it was. People were much more comfortable calling it mercy killing or euthanasia or something of that sort. But the media in general reported something like, "Tracy Latimer was a disabled girl who suffered from cerebral palsy and was confined to a wheelchair." That sounds pretty bleak. It sounds a lot different than saying, "Tracy Latimer was a young girl who had a disability, used a wheelchair, and had cerebral palsy." It doesn't sound nearly as horrendous, but because the media chose those words that drove home terms of reference about Tracy Latimer and the circumstances of her death, that made people much more sympathetic towards her father's crime. And I feel that that's just a fairly vivid example of how words are meaningful. Short of that, it's just plain to me that people with disabilities aren't disabled in every sense. They're people first. And they happen to have a condition that makes it challenging for them in some way or another to exist in the world. So they are people with disabilities, they're not broken as people. They're not disabled people. They're people with disabilities.

CTJ: In what ways does journalistic writing about disability differ from writing about disability used in other vocations?

RC: Maybe not a great deal. I think it's different in the sense that the topic matter [of *Abilities*] always surrounds disability lifestyle considerations. You don't see that consistently in most publications. Even though I said we're not an advocacy publication, we do like to highlight people who are doing things right in our view, as opposed to people who are making things more difficult in our view. I think I hesitate to say the "wow" factor, but the notion of "can-do" — the notion of being able — is important to have in the publication so that we're putting that kind of message out there so people get that in fact people with disabilities are able. And most often it's circumstances, it's the environment or it's the lack of technology that holds them back. But given those tools, given getting rid of handicapped conditions in the environment, and given the right technology, people with disabilities tend to be as able as anybody else, and sometimes more so because they value the importance of a good job perhaps more than others might because it's harder to come by. So I guess form that point there are some differences. But in terms of the topic matter, and in terms of the quality of writing I think we compare to other publications.

CTJ: In your opinion, does journalism reflect public opinion about disability or shape it?

RC: I think it, I think it does both. I mean, it reflects it. I guess it's a fine line. I don't think it shapes people who are knowledgeable about disability. I think it reflects disability issues to the mainstream who are less well informed about disability. And it either informs them or misinforms them. So I think there's a fair bit of that going one.

CTJ: Do you mean that the way disability is written in different types of media shapes people's understanding of disability?

RC: Yes. I think we know when people use inappropriate terms and inappropriate language. It shapes their perceptions in negative and inaccurate ways. And when you use language that is correct and more in keeping with the reality I think that similarly shapes attitude.

CTJ: Do you think journalistic language overall is disabling language?

RC: Yeah, still. I think it's improved a little, but not enough. You still hear about people being confined to a wheelchair, you still hear about disabled people, you still hear about suffering and the conditions people don't suffer from. You still have heroes larger than life and poster children being cuter than cute, and there's always something.

CTJ: So, in thinking about people who produce disability related media, what do you think are some of the challenges and restrictions they face in doing that?

RC: Well probably sorting the wheat from the chaff, in the sense that people often come into disability issues highly opinionated in one way or the other about something or the other. And they tend to espouse a single perspective. And I think that often there's a problem with that in anything, but particularly in the area of disability it's important to present the well-rounded picture of a given issue so that the reader is well informed. I think it's really important that people do make their own decisions about things, but the responsible thing to do is to make sure they get as much of the picture as you can give them.

CTJ: When it comes to accepting stories and pitches, how do disability-based stories catch your attention?

RC: Well, what we look for wherever possible is to have it come from a disability perspective. So either one person with a disability or a person who is intimately involved in disability issues. That's kind of a criteria for selection. Then we look for relevance. Is this more the kind of thing that would be better served by *Reader's Digest* or is it something that *Abilities* would choose? It would be a waste of our paper to print stuff that is preaching to the choir. That is letting people out there with disabilities know what we know they already know. So we exclude that kind of pitch. We look for innovative stuff, for breakthroughs. For different ways of doing things, for opportunities that we feel would be life enhancing for people with disabilities. And those are the kinds of things we like to go for.

CTJ: What do you think makes a good disability-based story?

RC: I think a good disability-based story would be something that first of all features disability as being central to it, and presents an innovation or a departure. Or an event that is related to disability that is newsworthy. That is likely to be of general interest.

CTJ: Do you face any barriers in telling these stories?

RC: Yes, because of the type of organization we are, we're not able to pay full writers' fees. So we operate on a system of honorariums. So almost by definition, more often than not people who write for us are not professional writers and so it takes a lot of work on our part to … bring that writing up to snuff so that it's considered to be journalistically worthy, so that's a challenge.

CTJ: Are there any types of disability that might stop you from choosing somebody as a subject in a story?

RC: No.

CTJ: In what ways do you think your work in particular impacts the public?

RC: Not enough. I feel that *Abilities* mostly travels within circles that have disability, and I'd like to see *Abilities* make mainstream hands so they can see the "able" in ability. So that they can have an understanding that people with disabilities generally are just people too.

CTJ: I'm writing on the premise that people should care about disability and journalism. But I'd be interested in hearing from you if you think people should care about that, and if so, why?

RC: Well, I think people should care about it because I think disability is a growing segment of our population in general. For those of us who are lucky enough to live long enough, we will experience disability first hand. We all, well nearly all of us, will experience disability in a very close way through a family or a friend. I think this is a trend that is going to become more intense. And I think it's responsible to be knowledgeable and to understand this question: what is the fabric of disability from that point of view?