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**When Bureaucracy and Policy Leave Ethics Behind:  
Our Nineteen-Day Battle with Alberta Health Services to Save Our (Independent) Lives**

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Having studied and worked in the fields of Disability Studies and Disability Ethics for over ten years now, I had reached a point where I *thought* I was thoroughly aware of—to use a disquieting, yet sadly appropriate, militaristic term—the *fronts* on which people with disabilities must wage ongoing battles in order to preserve our fundamental human rights and prevent our lives from being devalued in and by a society that seems to be becoming increasingly able-ist in its attitudes and actions. Beginning-of-life and end-of-life issues, such as selective abortion and euthanasia/assisted suicide on the basis of disability, access to appropriate medical care, access to employment—those were, to me, the readily-identifiably areas in which people with disabilities and their allies still had much work to do and many battles to fight in order to achieve full equality. But the right to self-determination through living independently in the community, with appropriate supports? The right to direct one’s own personal care? Those, thankfully, were *old* battles, battles that had been hard-fought, but eventually won, by previous generations of Canadians with disabilities in the 1970s and 80s. Now, they were “givens,” assumed rights, upon which I, like many other Canadians with disabilities, had been able to build a career, a home, a life.

But that seemingly solid foundation on which my current life and lifestyle had been built suffered a seismic shock in late May of this year. It came in the form of a letter from Alberta Health Services (AHS) to Creekside Support Services, the user-run Homecare service provider through which I, and fourteen other individuals with disabilities who live in Creekside

Condominiums, manage and receive our own homecare (read: personal care) services.

At this juncture, I think it incumbent upon me to point out that the following letter was the *first, and only*, direct communication that we had had from AHS since the Request for Contract Proposals was issued back in February 2013. Furthermore, it must be noted that, disturbingly, the entire proposal submission process was veiled in a strict code of silence—which amounted to nothing less than a gag-order: AHS informed all potential applicants that, if they discussed or asked questions about any aspect of the Request for Proposals with other applicants, anyone from AHS, or anyone else at all, they would automatically be disqualified from submitting a proposal. This, of course, begs the question: *What of transparency in the healthcare system?*

So, after 3 months of silence, we, the managers and users of Creekside Support Services) received the following letter from Alberta Health Services:

May 30, 2013  
Creekside Support Services Ltd.  
RE: **RFP SER2013-02-8091;**  
**“Request for Proposals for Home Care Services in the Calgary and  
Edmonton Zones”**

Dear Sir or Madam,  
Home care is an important part of the health care system. Alberta Health Services would like to thank you for taking the time to submit a proposal and for your commitment to home care.

This letter is to advise that you have not been selected to negotiate a contract with Alberta Health Services for home care services.  
Should you wish a debriefing in respect of your proposal, please contact...

Representatives from Zone Operations will begin contacting service providers the week of June 3rd to discuss next steps, contract terms, and transition planning for home care clients. Please note we will inform home care clients regarding the transition of providers and that we are all working together to best meet their healthcare needs. The care of Albertans is our first concern.

Home care is a growing need across the province and we want to ensure there is a fair and transparent process for contracted home care services. We are grateful to you for your compassion and dedication in providing home care services to Albertans. We will work closely with you during this transition to ensure individuals continue to receive the care they need. Thanks again for your continued support to make sure clients continue to receive the care they need throughout the transition.

Potentially lost in the banality of the Ra!-Ra! Client-Centered Care jargon is the fact that, with this letter (and identical letters received by the two other user-run homecare service providers in Edmonton: Abby Road and Artspace), AHS was announcing its decision to arbitrarily set the clock back 30 years for Albertans with disabilities. No longer were we to have any say at all in where, when, or by whom our personal care was provided. What this meant, in practical terms, was that, within the next four to six weeks, we were going to lose all of our current health care aides—many of whom had worked with us for six years or more; these aides—our aides—were to be replaced by workers from a third-party, for-profit homecare provider. Since the new aides would not be working directly for us, but rather for the third-party homecare provider, we were going to be forced to relinquish absolutely all control over who we would allow into our homes to provide us with essential, intimate care.

As one can probably imagine, my initial reaction to this letter, and that of my fellow residents, was complete and total shock. For the first few minutes and hours, it was all I could do to wrap my head around the fact that, without any kind of consultation whatsoever, AHS had essentially nullified 30 years of hard-won gains made by disability-rights advocates, who had fought for the right of people with disabilities to live independently in the community. I kept having thoughts like: *Canada is still a free, democratic country, isn't it? I'm still a tax-paying Canadian citizen, aren't I? If these things are still true, then how can Alberta Health Services have the right to arbitrarily blow up all three of the user-directed homecare services that an*

*entire generation of Edmontonians with disabilities had fought to establish and develop over the course of three decades?* My time to entertain these initial shock-motivated questions of HOW this could happen was very short. It *was happening*, and AHS had decreed that the transition in homecare providers was to be completed by August 1<sup>st</sup>. If we were going to launch any kind of campaign to try to stop this ill-conceived plan which would place our way of living—and, indeed, our very lives—in jeopardy, we had to begin that campaign *immediately*. Thus, in the blink of an eye, my neighbours, friends, and colleagues in the local disability community found ourselves in all-out war mode.

So, we hit the ground running—or at least driving in high gear! Sleep-deprived as we were from a sleepless night of worry (the first of many we would have over the next three weeks), the morning after the meeting that plunged us into war mode, my fellow “Creekside Crips” and I launched our campaign to try and affect a reversal of this wrong-headed, horrific decision. Our primary weapons in this campaign were traditional news media and social media. I set up a Facebook page entitled “Stop the Alberta Government’s Home Invasion and Assault on People with Disabilities.” During the course of our three-week campaign (which felt more like a *three-year* campaign) this Facebook page served as a sort of a repository for a collection of news articles, blog posts, and online discussions about AHS’s decision to change Homecare. My friend and neighbour, Cam Tait, a former reporter with the *Edmonton Journal*, dedicated his already-established blog to features, interviews, and posts by guest bloggers (including myself) about the impact that AHS’s decision to arbitrarily change homecare providers would have, not only on those receiving homecare services, but also on the staff who were currently providing these services. Disturbingly, we kept discovering new angles to explore in our blog posts and commentaries by observing the way in which things were unfolding at Abby Road, which was

about two weeks ahead of us in the "transition process". At the first meeting between homecare service users at Abby Road and representatives from their new service provider, Rivera, residents were told that, while workers from Rivera would still assist people to eat, they would not have time to do meal preparation. Abby Road residents who required meal preparation were consequently advised to look into getting Meals on Wheels. The more we learned about what life after the change in homecare providers would look like, the more fearful we were all becoming.

Then came the Monday morning, a week into our campaign, when Cam Tait and I shared a DATS bus. "Heidi, what do you think--" Cam asked me at a stop light, "What do you think of inviting Allison Redford for coffee on the blog?"

It took me a second or two to realize that he was serious. I shrugged, "Sure, why not? – it certainly can't hurt!" Cam composed the invitation and posted it on the blog that afternoon:

Dear Ms. Redford:

Let's have coffee this week. We have a lot to talk about, you know. People with disabilities have yelled, and screamed and slammed many doors last week in frustration hearing the Alberta government is making changes to home care. We are scared. We are nervous. And we are wondering why this is happening to us when we weren't even consulted.

But we are willing to put that behind us. We want to talk about the future and we want to ensure the best future for ourselves and our families ... just like every other Albertan. We want to work with the government, have open discussion and tell you, face to face, why there isn't any need to change it. We want to show you how we can, in fact, save the government money with non-profit groups.

We are not alone in our view. We began an on-line petition Saturday night, and as of 10:30 a.m. Wednesday, we had 843 people sign it. And it's growing.

All we want to do is talk, and share ideas. Please consider this. And, given the home care cuts, suggesting the government doesn't have much money, how about this: we'll even buy coffee.

Concerned persons with disabilities.

The next morning, I had an idea and emailed Cam: "Hey, do you think maybe I should email the

invitation you posted on the blog directly to Redford's office?" Cam's reply was almost instantaneous: "Not now, but RIGHT NOW!" Within five minutes, the coffee invitation was emailed to the Premier's office and cc'd to the office Health Minister, Fred Horne.

Late that afternoon, we, the homecare service users at Creekside, had our previously-scheduled meeting with representatives of AHS homecare to discuss the transition. A long-time friend of mine who lives in Calgary came up to attend this meeting with me, both to help facilitate others' understanding of my speech and to offer me moral support. As it turned out, both were equally needed. After the meeting was adjourned, my friend turned to me and declared, "I'm glad I came up for this; if I hadn't actually been here myself, I think I would have had a hard time believing what went down here!" He was referring to the through-the-looking-glass moments of illogic, indifference and arrogance that had characterized the response we received from AHS homecare representatives during the just-completed meeting. Over and over again throughout the hour-and-a-half-long meeting, the mantra repeated by the representatives of AHS Homecare was: "Your care-plans will continue to be followed to the letter; *the quality of your care WILL NOT CHANGE.*" Indeed, when pressed to answer specific questions, such as, "How would an outside homecare provider be able to provide 24/7 service, when the bylaws of our condo board would prohibit them, as 'outsiders,' from using the office and staff room space currently used by our 'in-house' support services?", the only response offered by the representatives of AHS Homecare, who grudgingly admitted that they were not aware of this Condo Board policy, was, "We will work with the new provider to ensure that your care-plans will continue to be followed to the letter; *the quality of your care WILL NOT CHANGE.*" Ultimately, we insisted that we were simply unprepared and unwilling to proceed with any further talks about transition unless or until the question of 24-hour care was satisfactorily

addressed. Disturbingly, this prompted the following response, "Unfortunately, the contract starts August 1, the longer we take in getting [the new service provider] ready, the more problematic the transition will be."

Despite the tough front we maintained throughout this meeting with AHS Homecare, its conclusion left us all feeling, not triumphant, but rather immensely drained, and, indeed, bullied. It seemed as though, no matter what we said or did, AHS was going to force this change upon us—consequences, and our lives, be damned. But by mid-morning the next day came game-changing news: Cam got an email from Premier Redford's office; she and Dave Hancock, Minister of Human Services, wanted to meet with us that Sunday morning. Once again, we were in shock. But, for the first time since this whole nightmare began, we felt real hope that there could yet be a positive conclusion to all this.

So it was that on the following Sunday morning, Larry Pempeit (the President of Creekside Support Services), Cam Tait, and I went to the Legislature to meet with Premier Redford and Minister Hancock. (Personally, I was especially grateful that this miraculous meeting was taking place on a Sunday morning because it meant that the congregation of my church was providing us with real-time prayer backup!) During the meeting, we shared our concerns about the heavy-handed way in which AHS made and announced their decision to make this change our homecare provider without including us in any sort of consultations. Ms. Redford was especially interested in how this was handled. "I want to make sure I understand this," she said several times while her aides were busy taking notes. She said she was unaware of how things were handled, especially when CSS users have direct input in the care we get. We told her we planned to fight the battle to the end, July 31, when our contract was due to expire. Ms. Redford said she would look into the Creekside situation as well as that of Abby Road and

Art Space. "We have work to do," she said near the end of the meeting. As we left the meeting, we couldn't help but feel a new sense of hope for our situation because of Ms. Redford's willingness to have a truly open discussion about the matter.

In the end, the resolution of our battle came much sooner than any of us had dared even dream. Two days after our meeting with Ms. Redford, came the announcement by AHS that they were reinstating the contracts of Creekside, Abby Road, and Art Space. All I could do for the first fifteen minutes after receiving the email informing me of this development was sit at my computer and cry with relief. Such had been the intensity of the battle.

It would be comforting to be able to end this article by asserting that this was an isolated case in which the well-being—and, indeed, the lives—of Canadians with disabilities were threatened by bureaucratic policies, or that the outcome of this particular battle has secured a new level of protection for people with disabilities against future governmental assaults on our freedoms and our lives. Sadly, neither assertion would be true. In fact, at the time of this writing (almost two months after their reinstatement was announced), the three user-run homecare service providers in Edmonton have yet to receive long-term contracts from AHS, and are currently still only operating on month-to-month provisional contracts. More broadly, the province of British Columbia is poised to follow Alberta's lead in responding to provincial budget deficits by cutting back on services for people with disabilities, including homecare services. In the same vein, Ontario is preparing to merge its Ontario Works Program (formerly known as "General Welfare") with the Ontario Disability Supports Program; Ontarians with disabilities will thus be forced to either find work (which is often impossible in a competitive market), or starve. The increasing recurrence of this kind of systematic dismantling of services and supports for people with disabilities across the country must be a wake-up call—a catalyst for

increased vigilance and a new, unprecedented level of cooperation among Canadians with disabilities. It is becoming alarmingly clear that the basic rights, for which we have fought for decades, are being systematically threatened. I believe that it will take nothing less than a unified, organized effort by all Canadians with disabilities, and their allies, to preserve our rights and save our lives.