

**DisAbled Women’s Network of Canada**

**Réseau d'action des femmes handicapées Canada**

Speaking Notes

Study of Eating Disorders Amongst Girls and Women with Disabilities – Status of Women Standing Committee

February 26, 2014

***Leadership, Partnership & Networking***

About the Disabled Women’s Network of Canada (DAWN-RAFH Canada)

DisAbled Women’s Network (DAWN-RAFH) Canada is a national, feminist, cross-disability organization whose mission is to end the poverty, isolation, discrimination and violence experienced by Canadian women with disabilities and Deaf women. DAWN-RAFH is an organization that works towards the advancement and inclusion of women and girls with disabilities and Deaf women in Canada. Our overarching strategic theme is one of leadership, partnership and networking to engage all levels of government and the wider disability and women’s sectors and other stakeholders in addressing our key issues.

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Author Biography

She is President of the Disabled Women’s’ Network of Canada (DAWN-RAFH Canada, www.dawncanada.net). Carmela is a Member at Large of the Executive Committee of the Council of Canadians with Disabilities. (www.ccdonline.ca). She is a director with the Canadian Centre for Disability Studies (www.disabilitystudies.ca).

Carmela is President of the Alberta Network for Mental Health (www.anmhf.ca) and a Lifetime Member of the National Network for Mental Health (www.nnmh.ca). She is a founding member of the Canadian Coalition of Alternative Mental Health Resources (www.ccamhr.ca). She a Vice-Chair of the Alberta Alliance on Mental Illness and Mental Health (www.aamimh.ca). She is on the Steering Committee of the Alberta Disabilities Forum and is a member of their Mental Health and Disability Working Group.

Carmela is Co-Chair of the Action Committee on Disabilities and Abuse. She is also a Board Director of the Rocky View Regional Handibus Society (www.rockyviewbus.ca). She is the Functional Needs Coordinator of the Irricana Emergency Management Agency. Carmela has received the 2007 Council of Canadians with Disabilities Award Contribution to the Disability Rights Movement in Canada and the 2003 Nadine-Sterling Award for Self-Disclosure and Commitment to Consumer Based Initiatives.

**Study of eating disorders amongst girls and women**

Hello, I am Bonnie Brayton, National Executive Director of DAWN-RAFH Canada. I bring greetings from my President, Carmela Hutchison and our Board of Directors. I want to begin by acknowledgement of the Algonquin peoples on whose traditional lands we are gathered today.

Our remarks today will add the unique perspective DAWN-RAFH Canada brings to the table that have profound impact on the subject of eating disorders. We will aim a disability, feminist and intersectional lens on eating disorders in order to shed an additional light to add to the discussions and most importantly, the interventions that will come from these deliberations.

In the Convention on the Rights of People with Disabilities Article 6 identifies “women and girls worldwide as a focus of special concern because of the multiple barriers we face”, yet the reality is that intervention in the problems we face is not keeping pace and the gap is widening. This is, in part, is the disability of our society to address women and girls in the context of those multiple barriers. An inability to prevent violence against women and girls with disabilities, a lack of access to an appropriate level of treatment or the supports such as income support, access to education and safe child care to allow a woman to recover. The Intersectional Lens is an attempt to understand how multiple forces work together and interact to reinforce conditions of inequality and social exclusion”. (from <http://criaw-icref.ca/sites/criaw/files/Everyone_Belongs_e.pdf>, p42, Everyone Belongs - A Toolkit for Applying Intersectionality, By Joanna Simpson CRIAW/ICREF,June 2009).

“The actual face of an eating disorder is heterogeneous: mostly female, but also male; individuals who identify with their assigned sex and gender, and those who don't; racialized individuals; newcomers to Canada and established Canadians; individuals with physical disabilities; individuals with concurrent medical or psychological disorders, such as, diabetes, substance abuse, depression, PTSD, and so on. Individuals from all socio-economic walks of life have eating disorders. Merryl Baer NEDIC, 05 Feb

From a feminist lens, feminism throughout her story has long been concerned with the messages women and girls receive about body image, sexuality and, in particular, the sexualization of young girls in the media. In the quest to present women as strong and capable, feminism in turn also sometimes does not reflect the face of women and girls with disabilities. We look everywhere, but do not see our faces, and often there is no place for us. No models to follow.

In the intervening time, we also see the deadly and devastating impacts of internet pornography and cyberbullying. Women and girls being are exposed to online sexual harassment and stalking. Sex is a commodity and your stock rises and falls with your appearance. Internet addiction is becoming a focus of treatment on pediatric units at home and abroad. It is becoming harder and harder for women and girls to escape the deadly effects of violence against them, and the violence is becoming easier to perpetrate with a few simple clicks on a smartphone.

No exploration of media and eating disorders would be complete without flagging the issues posed by online groups that are involved in trading ideas about how to binge/purge and further reinforcing deadly practises. Indeed body image issues are also emerging for boys and men as well, though women and girls remain most affected.

Additional impacts also come in the media for our virtual invisibility, and for the way society views mental illness and invisible disabilities, refining our view to the context of disability:

“People with mental disabilities tend to come at the bottom of the hierarchy of impairments, below those with physical and learning disabilities, because they are constructed as deviant and dangerous (Beresford, 1993: 21), as possessing a spoiled identity and lacking rationality (Beresford and Wallcraft, 1997: 77). The media plays a fundamental role in this portrayal focusing on the strange or aggressive behaviour of people categorised as 'mentally ill'. This has real consequences for individuals living with such disabilities because politicians are affected by what is reported and shape policies around mental health accordingly.” (<http://dsq-sds.org/article/view/356/459>)

Violence against women and girls with disabilities, in particular sexual violence, is identified as part of the cause of eating disorders. In its entirety, Article 16 of the Convention on the Rights of Persons with Disabilities upholds the need for people with disabilities to be “Free from all forms of Exploitation, Violence, and Abuse”. Yet in our country, women and girls with disabilities have higher rates of violence:

“In a study comparing the rates of instances of sexual and physical assault among women with and women without disabilities, it was determined that women with disabilities were four times more likely to have experienced a sexual assault than women without disabilities[[1]](#endnote-1)” (DAWN-RAFH Canada Fact Sheet)

Women with disabilities also experience greater forms of violence because of their unique risk as the result of their disabilities:

“Disabled women are at risk of violence in many forms – neglect, physical abuse, sexual abuse, psychological abuse and financial exploitation. Women and girls with disabilities are at a high risk of experiencing gender-based and other forms of violence due to social stereotypes that often serve to reduce their agency by infantilizing, dehumanizing and isolating them, making them vulnerable to various forms of violence, including institutional violence. Women with disabilities are exposed to additional risks of abuse by caregivers who provide services specifically related to her disability. Women with disabilities experience sexual violence in various forms such as; violations of privacy, restraint, strip searches, and solitary confinement that replicate the trauma of rape, rape by staff and other inmates/residents of institutions, forced abortion and forced sterilization.” (DAWN-RAFH Canada Fact Sheet)

“Many of us recount our experiences, as young children, of having to display our bodies to groups of male doctors in the guise of “medical treatment” without prior knowledge or consent. We may have been asked to strip, to walk back and forth in front of complete strangers so that they could get a better view of what the physical “problem” is, or to manually manipulate our limbs to determine flexibility and dexterity. Today, pictures or videos are taken of us and used as educational tools for future doctors, with little thought given to our needs to have control over what happens to our bodies or who sees us. While the medical profession attempts to maintain control over our bodies, some women with disabilities may attempt to regain control through dieting, bingeing or other methods of body mutilation.” (Body Beautiful/Body Perfect: Challenging the Status Quo – Where Do Women with Disabilities Fit In?, Francine Odette, M.S.W., DisAbled Women’s Network, <http://nedic.ca/body-beautifulbody-perfect-challenging-status-quo-%E2%80%93-where-do-women-disabilities-fit>, 1993)

In an web article on Spinal Cord Injury and Body Weight, the recommendations are:

The registered dietitian should estimate ideal body weight for persons with spinal cord injury by adjusting the Metropolitan Life Insurance tables for individuals of equivalent height and weight. There are two reported methods for adjusting the tables:

• Quadraplegia, reduction of 10% to 15% lower than table weight; paraplegia, reduction of 5% to 10% lower than table weight

• Quadriplegia, 15 lbs to 20 lbs lower than table weight; paraplegia, 10 lbs to 15 lbs lower than table weight. <http://andevidencelibrary.com/template.cfm?key=2305&auth=1>

It is ableism at play when a doctor asks a woman with a disability to lose weight before she becomes too heavy for her caregivers to lift. And that ableism persists when a woman with a physical disability loses weight, and instead of asking how she did it, congratulates her on her “success.” Disability Studies Quarterly, Summer 2002, Volume 22, No. 3, pages 6-20 <www.dsq-sds.org>Copyright 2002 by the Societyfor Disability Studies; Anorexia: Illuminating Impairment or Dishonourable Disability? Stephanie Tierney, BA, MA Centre for Evidence-Based Social Services University of Exeter

Such demands on a woman or girl with a disability to achieve such a standard are obvious why she might develop an eating disorder. One woman known to our organization refused to drink milk to prevent osteoporosis that comes with menopause even though begin a wheelchair user put her at increased risk for osteoporosis. She went onto experience a fragility fracture of her hip. She is an abuse survivor. She has been experiencing electrolyte imbalances. She also had been taking an alternative colonic cleansing therapy, and following a strict diet. She is one woman we know of.

Though identified as a serious environmental risk factor for Eating Disorders, every psychiatrist who testified spoke about the active discrimination faced by women and girls with eating disorders. This discrimination is in clear contradiction of the spirit of article 16 (4) of the Convention which addresses the responsibility of States Parties in assisting people to recover from the injuries posed by their abuse:

“to ensure there are all appropriate measures to assist people with disabilities to be treated for their injuries and have opportunities for recovery that respect the health, welfare, self-respect, dignity, autonomy, taking into account the gender and age specific needs”. (CRPD)

DAWN-RAFH Canada also supports the recommendations made the medical professionals presenting here and those of the NEDIC we offer a discussion of our own:

1. Canada’s approach to eating disorders must be strategic, and involve all levels of education, practise and research. We need to ensure the intersectional, gender and disability lenses are also trained on the process of research, practise and education, public awareness and disability inclusion. Public Health measures aimed at prevention and early detection must include physician screening, public health nurse screening, school nurse, mental health and addiction screening as a well as the intervention and recognition that violence against women and girls is a cause, effect and risk factor for eating disorders. Women and girls need choice and a continuum of referral points. Caution is also urged in the area of interventions such as neurostimulation and magnetic stimulation, there is promise, but have the risks also been accounted for?.
2. There are many references to Best Practices and evidence based care but there must be room for Innovation, new ideas and also creative care for women and girls with disabilities for whom evidence based interventions are not working.
3. In his presentation, Dr Woodside noted: “We waste tens of millions of dollars when we could invest this money in Canada to provide treatment for people in their own country.” We need Canadian made solutions by Canadians, for Canadians.

1. We must ensure women with disabilities and girls are included in the discussion of eating disorders, violence against women and girls with disabilities, body image. Our voices perspectives and images are necessary in order to move forward effectively. InFocus project one way to collect and garner people with disabilities community input. Treatment opportunities that include women and girls with disabilities and take into account the intersection of gender, violence and disability is paramount. The services need to be competent in addressing eating disorders, trauma, addictions, and medical effects of eating disorders and disabilities of women and girls who present for treatment rather than using intersecting disorders as a rationale for exclusion. We note the mention of three agencies in particular during these presentations: Sheena’s place, Garden of Hope and Danielle’s place, but it is not known if there are any services for women and girls with disabilities other than eating disorders nor if their information is available in alternate formats or if they are accessible for people with disabilities. Treatment must be holistic, multidisciplinary, and offer a range of range of choices along a continuum of peer support, community treatment, day programs, brief intervention and long-term treatment. The interventions must take the developmental level of the woman or girl with a disability into account and be appropriately tailored for their needs. There is a lot of discussion in the presentation about the concurrent addiction but not much discussion on the appropriateness of addiction treatment modalities in helping manage compulsive aspects of the eating disorder. More research is needed to help see if addictions modalities could assist Eating Disorder treatment.
2. Remove barriers to mothers with disabilities and eating disorders who need to go to treatment. In Alberta, under the Child, Youth and Family Enhancement Act, if a child is in care for 200 cumulative days in care they move to make the child to a permanent guardianship order. If a mother has no other place to care for her children but temporary foster care, this is a discriminatory measure. We are not sure if this measure is similar in other provinces. In order to provide a structure and framework for therapy, access for determinant of health must be in place.
3. Justice has a role to play with Mental Health Diversion and Elizabeth Fry for people arrested for stealing to finance binge cycles, as well as ensuring adequate treatment opportunities exist for Women and girls with disabilities. There is a role for justice as well in intervention against violence against people with disabilities, and with cyberbullying, stalking and other forms of harassment and violence.
4. Women and Girls with disabilities must have positive media coverage. Women and Girls with disabilities must have access to programming in which they can see their own lives and realities reflected in the Canadian discourse. CRTC need to be more active in promoting these measures.

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| Ever mindful of the slippery slope to assisted suicide we look at the risk for women with disabilities being valued less for scarce treatment resources because the younger person was perhaps seen as more viable so she, as a 53-year-old woman, was left for “nature to take its course”. Evidence given by Dr Woodside 28 Nov 2013. In countries where euthanasia exists, like the case of Ann G, the 44 year old woman with anorexia nervosa dying by euthanasia, is one of a series of cases that have come out in Belgium.(<http://alexschadenberg.blogspot.ca/2013/02/belgian-woman-with-anorexia-nervosa.html>) The human family in Canada simply must offer better than this to its citizens.  Thank you. |

1. [↑](#endnote-ref-1)