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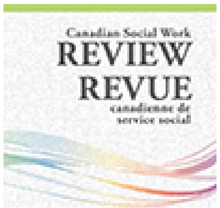

(dis)ABILITY RIGHTS

A Forgotten Claim

Judy E. MacDonald

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(dis)ABILITY RIGHTS
A Forgotten Claim

Judy E. MacDonald

SOCIAL WORK NEEDS to be aware of ableism, (dis)Ability discrimination, and the oppression of people with (dis)Abilities. The probability that we ourselves will experience a (dis)Ability within our lifetime is close to 100 % (Zola, 1982). Further, given the statistics cited below, there is a strong likelihood that social workers, regardless of their field of practice, will work with clients who are (dis)Abled. In Canada 14.9 % of women and 12.5 % of men identified as living with a (dis)Ability that impacts their activities of daily living (Burlock, 2017). Provincially, this statistic ranges for women between 9.8 % in Quebec to 16.6 % in Manitoba; and for men between 8.9 % in Quebec to 15.8 % in the Atlantic region. Indigenous women have the highest percentage of (dis)Ability with 22 %, compared to 14.7 % for non-indigenous women; whereas the difference between Indigenous men and non-indigenous men is not as significant, 14.6 % compared to 12.5 % (Burlock, 2017). Fifteen point seven percent of (dis)Abled women have obtained a bachelor degree whereas 30.7 % of women without a (dis)Ability have a bachelor degree. Women with (dis)Abilities continue to be the lowest paid ($58,870) in comparison to women without (dis)Abilities ($79,130) and men with ($61,530) and without ($81,310) (dis)Abilities. The poorest of the poor in Canada are women living with (dis)Abilities, for according to Dawn Canada (2014) their average annual income is $8,360.

Note: Historical references to people with (dis)Abilities are written in italics and placed within single quotation marks. This is done to draw the reader's attention to the stereotypes and judgments placed upon (dis)Abled persons; stereotypes that linger today.

Judy E. MacDonald is a member of the journal's editorial board. She is also Director of the School of Social Work and Assistant Dean, Equity and Inclusion in the Faculty of Health at Dalhousie University.

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People with (dis)Abilities face economic oppression as the more severe the (dis)Ability the greater their chance of living in poverty (Wall, 2017). They deal with social marginalization created in part through limited access to transportation. For example in Nova Scotia Access-A-Bus is only available for medical appointments booked a week in advance (Halifax Access-A-Bus, 2013); the thought of a (dis)Abled person using this service to attend a concert or to go to the bar with friends is unthinkable. People with (dis)Abilities experience psychological abuse sometimes delivered through public stares or worse, being totally ignored, and made to feel invisible (Garland-Thomson, 2009). Physical barriers, such as inaccessible physical structures like stairs or heavy doors keep (dis)Abled people isolated or dependent upon others for assistance. Discrimination can also come in the form of political discrimination where people with (dis)Abilities' voices are not heard and their concerns and needs are not validated (MacDonald, 2016). For example, it was only after organized protests and strategic lobbying that people with (dis)Abilities were included in the Canadian Charter of Rights and Freedoms(1982);(dis) Abled people were almost left out of this foundational bill of rights that forms the first part of the Canadian Constitution.

Historical Oppression of the (dis)Abled

The oppression and exploitation of (dis)Abled people dates back to the beginning of known civilization. The Greeks and Romans both exercised infanticide for children who were born showing obvious signs of imperfection (Barnes, 1997). More recent history included practices of locking (dis)Abled people away in state institutions (Mackelprang & Salsgiver, 2015), sterilizing them against their will (MacDonald, 2016) and targeting them as victims of eugenics (MacDonald & Friars, 2010). In her film *Almost Normal* (2004), Dr. Seana Kozar recounts how her parents were encouraged to institutionalize her when they were told of her Cerebral Palsy diagnosis shortly after she was born. The doctor believed Seana would be an '*invalid*' with limited capacity and therefore it would be in everyone's best interest if she was put in an institution. Thankfully her parents did not accept the advice. Today Seana is a PhD graduate, a film director, a partner and a mother, among many other things.

Leilani Muir was not as fortunate, as she was admitted to the Provincial Training School for Mental '*Defectives*' in Alberta at ten years of age. *Muir vs The Queen in the Right of Alberta, 1996* is a landmark case that ended with Leilani being awarded $740,780 for wrongful sterilization and wrongful confinement. When Leilani was 15 she was told she needed to have an appendectomy, however this was a calculated deception for forced sterilization resulting in a hysterectomy along with the removal of her appendix (Muir vs The Queen in the Right of Alberta, 1996; Withers, 2012). This deception was not revealed to Ms. Muir until she tried to conceive as an adult woman. Leilani came from an abusive home where she was denied food, yet one of the noted behaviours on her training school admittance form was that she took lunches from other children at school. Leilani was classified as a '*moron*' yet no psychometric testing was done to confirm this diagnosis (Muir vs The Queen in the Right of Alberta, 1996). Sterilization of (dis)Abled women did not stop in Canada until the 1970s.

One of the most grievous examples of abuse came with Hitler's T-4 eugenics program from 1939 to 1941, aimed at "purifying the race" (Chadwick, 2003). Between a quarter and a half a million (dis)Abled people were killed. Propaganda portrayed the (dis)Abled as '*subhuman*' and their murders as 'mercy killings' (Mackelprang & Salsgiver, 2015). Publically, the Nazis were perceived as eliminating the suffering of people with (dis)Abilities', when in fact they were using them experimentally to perfect the gassing method.

Human Rights and Inclusive Policies

(dis)Ability advocates in North America gained voice and societal position from the Civil Rights Movement of the 1960s. A group of (dis)Abled students at the University of California at Berkeley organized with the purpose of promoting the rights of (dis)Abled persons and improving their quality of life (Rosenthal, 2013). When Ed Roberts arrived on campus in 1962 he was told, "we've tried '*cripples*' before and it didn't work" (Nielson, Nakamura, Kleege, Mejia, & Nasir, 2018). (dis)Abled and non-(dis)Abled students were protesting, "challenging negative attitudes and stereotypes, rallying for political and institutional change, and lobbying for the self-determination of a minority community" (Anti-Defamation League, 2005).

Many have championed (dis)Ability rights from (dis)Abled Vietnam veterans aligning with (dis)Abled Americans to advocate for the *Americans with Disability Act – 1990* (Donowho & Sawalich, 2007), to (dis)Abled Canadians protesting on Parliament Hill to have people with (dis) Abilities protected under the *Canadian Charter of Rights and Freedoms – 1981* (Peters, 2003).

Globally, the *United Nations Convention on the Rights of Persons with Disabilities* has been signed and ratified by 177 countries since its inception in 2007 (United Nations, 2008 – 2015). There are 11 countries that have signed but have yet to ratify the Convention (including Cameroon, Lebanon and the United States) and ten countries where no action has taken place (including South Sudan, Somalia, Saint Kitts, and Nevis). Canada was one of the first countries to sign the convention, putting the country's signature to commitment of (dis)Ability rights and equality when the convention was presented in New York on March 30, 2007. However, things slowed down in the ratification process as it took three years to have it passed through the House of Commons—it was ratified on March 11, 2010 and came into effect on April 12, 2010. The ratification process brings the international UN treaty into law within the host country. Countries, such as Uganda, Thailand, Sudan, and Turkey all ratified the convention before a country with an international reputation for the promotion of human rights - Canada. The United States signed the convention but failed to pass it through Senate falling six votes shy in December, 2012. As a form of monitoring compliance to the treaty, progress reports are required two years after ratifying the convention followed by every four years thereafter (United Nations, 2008 – 2015). Canada submitted the first report, which was prepared collaboratively by the federal and provincial/territorial governments in 2014, four years after ratifying the Convention (Minister of Canadian Heritage and Official Languages, 2014). The Convention on the Rights of Persons with Disabilities "came into existence through a forceful call from persons with disabilities around the world to have their human rights respected, protected, and fulfilled on an equal basis with others" (United Nations Human Rights, 2014).

Commonwealth countries, such as the United Kingdom and Australia, along with the United States, all legislated *Disability Discrimination Acts* in the 1990s (Prince, 2010). In 2008, a Canadian parliamentary committee recommended "that the federal government, in consultation with provincial and territorial governments and stakeholders, continue to develop and implement a national disability act to promote and ensure the inclusion of people with disabilities in all aspects of Canadian society" (Standing Committee on Human Resources, Social Development and the Status of Persons with Disabilities, 2008, p. 3.17). Years later, Canada is still without a federal policy addressing disability discrimination but there are glimmers of hope in the forecast. For example, on November 22, 2017, Prime Minister Justin Trudeau announced a National Housing Strategy that would include 2400 affordable housing units for people with developmental (dis)Abilities (CACL, 2017). Provincially, Ontario led the way with accessibility legislation passed in 2005, followed by Manitoba in 2013 and most recently Nova Scotia in 2017. British Columbia is pushing hard for similar legislation (AODA, 2017). *The Accessibility of Ontarians with Disability Act, 2005* aims to have the province accessible by 2025 (Ministry of Economic Development, Employment and Infrastructure, 2008); Nova Scotia's *Accessibility Act, 2017* goal is to have the province accessible by 2030 (Department of Justice, NS, 2017). The pendulum, with respect to the social positioning of (dis)Abled persons, is swinging as it moves away from discrimination, segregation, ridicule, pity, and disgust toward access, accommodation, integration, and inclusion.

Still Work to be Done

Violence

While legislation and policy are moving toward full citizenship for (dis) Abled persons, oppression and abuse remain a topic people with (dis) Abilities are all too familiar with. News headlines tell the story: "Tragic and Unnecessary Death"(Bartko, 2018), "Isolated property denied Betty Anne Gagnon social supports" (Zabjek, 2017). These headlines describe the story of Betty Anne Gagnon, age 49, who died while in her sister and her brother-in-law's charge. The courts determined the couple, Denise and Michael Scriven, "(failed) to provide the necessities of life." Betty Anne had a developmental (dis)Ability and needed help with functions of daily living. She also enjoyed looking at teen magazines, dreaming of owning an RV, and bowling. Living with the Scrivens, Betty Anne suffered frequent physical beatings, was made to drink bleach, and was kept in a cage in the garage. On the night of her death, Betty Anne was in a run-down school bus, with no heat or bathroom facilities. It was a cold November night in Alberta where the average nightly temperature ranged between -13 and -8 c. "At the time of her death, the five-foot-two-inch mentally disabled woman weighed only 65 pounds. She had bruises on her body, two black eyes and blood in her nose . . . she had a fecal stone in her intestine and feces in her ears" (Warnica, 2013). Despite desperate cries for help from Betty Anne's family, the system failed her. They were bounced from police to social services, to another department who sent them to the department for elder abuse. The department of elder abuse then sent them back to the police with a request to go check on Betty Anne.

The DisAbled Women's Network of Canada (2014) indicates 60 % of women with (dis)Abilities are likely to experience violence during their lifetime. This is a statistic that all social workers should know, for only with awareness comes action and only through action comes change.

Discrimination

Nico, a 13-year-old youth with Down syndrome loves to play soccer with his family and listen to his father play the guitar. In 2012, he immigrated to Canada from Costa Rica with his family. His father is a professor at a Canadian university. Nico was denied permanent residency in Canada because his health condition could place 'excessive demands' on Canada's health and social service systems. More specifically, the government estimated that his school accommodations could cost between $20,000 and $25,000, yet currently Nico attends a public school with no additional accommodations (McQuigge, 2016). Section 38(1) of the Immigration and Refugee Protection Act (Government of Canada, 2001) states that "a foreign national is inadmissible on health grounds if their health condition (c) might reasonably be expected to cause excessive demand on health or social services."

Karalynn, a six-year-old child living with global developmental delay and epilepsy, loves to play on the trampoline and build things with Lego. She immigrated to Canada from Colorado in 2013 with her parents and siblings so that the family could start an outfitting wilderness business. She was also denied permanent residency. According to the Immigration Act, if it is estimated that a person with a (dis)Ability will cost more than $6,387 annually for health and/or social services then they are believed to be a risk for putting 'excessive demands' on the system, which will result in their application being denied (CBC, 2017; McQuigge, 2016). South of the border, where threats to human rights seem to be a daily occurrence, the United States does not discriminate in permanent residency applications against (dis)Abled children (US Department of State).

Nico and Karalynn's cases are a clear violation of people with (dis)Abilities' rights and freedoms. Both cases were overturned on compassionate and humanitarian grounds. Dr. Montoya, Nico's father, stated, "I think the disability community doesn't deserve compassionate and humanitarian considerations, but rather justice and means of inclusion into society" (McQuigge, 2016). Between 2014 and 2016, a total of 1,100 applicants found themselves being denied permanent residency due to a family member's (dis)Ability (Russell & Hill, 2017).

Housing Crisis

The UN Convention on the Rights of People with Disabilities specifically highlights the right to housing under Article 19, "Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live" and Article 28 states "…parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing" (United Nations, 2014). Yet within Canada it is estimated that 45 % of the homeless live with a (dis)Ability and that persons with (dis)Abilities have limited choice, if at all, when it comes to housing (Alzheimer Society of Canada, ARCH Disability Law Centre, CACL, CMHA, CCD, Institute for Research and Development on Inclusion and Society, Social Rights Advocacy Centre, & Wellesley Institute, 2017). Noreen, a 61-year-old and her two dogs, Gypsy and Kako, lived in her 2006 Jeep Liberty for almost a year after being laid off from her teaching position at a local university (Anderssen, 2017). Michelle, a 42-year-old who lives with a learning (dis)Ability and epilepsy, struggles with income assistance to find affordable housing, and fears she will be on the street with nowhere to go (Luck, 2016). Noreen lives in Victoria and Michelle in Halifax, illustrating the housing crisis reaches from one end of the country to the other.

There are multiple barriers to housing for (dis)Abled persons, from poverty to discriminatory practices of landlords, to a lack of supportive housing options. The statistics are overwhelming, with estimates of 400,000 plus people with significant (dis)Abilities having ‘core housing need,’ along with 520,000 people with mental health (dis)Abilities being homeless or in precarious housing conditions. Thirty-two percent of Indigenous people live with a (dis)Ability with 40 % living in poverty. In major urban centres between 20 and 50 % of the homeless are Indigenous. “The intersection of Indigeneity and disability, with scarcity of community supports for Indigenous persons living off-reserve, creates severe unmet housing and support needs” (Alzheimer Society of Canada et al. 2017, p. 6).

As many as “13,200 adults with intellectual disabilities aged 30 and older live with their parents because they do not have the resources or community support to live in their own homes” (Alzheimer Society of Canada et al., 2017, p. 4). Further, people with intellectual (dis)Abilities who are under the age of 65 ($n = 10{,}000$ nationally) are living in hospitals, nursing homes or long-term care facilities. Warehousing (dis)Abled people in this fashion is completely unacceptable. It is a dumping station where the person’s learning needs are not being met, socialization is not with their peer group, and integration into the community is forgotten. “Institutionalization by default” (Alzheimer Society of Canada et al., 2017, p. 4) is the term coined for this clear violation of the UN Convention of the Rights of People with Disabilities. Prime Minister Trudeau’s announcement of 2,400 housing units for people with developmental (dis)Abilities will only put a small dent in the housing crisis.

Conclusion

There is no question that people with (dis)Abilities’ rights and freedoms are more respected today then they were 70 years ago, but is the equity and inclusion of (dis)Abled persons evident throughout our society? Within this reflection issues of violence, discrimination, and oppression were only touched upon. Many more stories exist of (dis)Abled persons being segregated from society, denied equitable employment, or viewed as societal burdens. Social workers can have an impact on access and inclusion of (dis)Abled persons. We can bring stories forward, put pressure on lawmakers to write inclusive policies, advocate for affordable housing, adequate income, and supportive structures so that people with (dis)Abilities can be active members of communities. We need to pressure the Canadian government to live up to its commitment to the UN Convention on the Rights of Persons with Disabilities, and we need to lobby for a national disability act. Hopefully, over the next decade (dis)Ability programs and services will strengthen and the protection and integration of (dis)Abled persons will become the norm as our social policies take a progressive lens to (dis)Ability that is founded on the principle of full citizenship.

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