



PEI Advisory Council on the Status of Women

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April 10, 2008

Disability Services Review Committee
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Dear Ms. Cairns and panel members:

On the morning of April 2, 2008, representatives of the PEI Advisory Council on the Status of Women attended the sixth public hearing of the Disability Support Services Review in Charlottetown. At that session, your panel heard a wide variety of detailed and well-informed feedback on Disability Support Services. We have no doubt that similar issues were raised at the other public hearings you held.

BACKGROUND

Key Messages from Consultations: What We Heard

We heard the following recommendations from community organizations and individuals:

- Call for a new and better assessment tool to replace or supplement the FIM tool; also, for additional evidence (such as medical records and advice) to be considered in assessments, if this can be done without compromising confidentiality and privacy of individual patients.
- Call for changes to monthly ceilings for

About the PEIACSW Mandate

The Prince Edward Island Advisory Council on the Status of Women (PEIACSW) is a provincial government advisory body dedicated to supporting women's full and equal participation in social, legal, cultural, economic, and political spheres of life.

The nine-member, government appointed Advisory Council regularly works in collaboration with government and community groups, undertakes research on issues of concern to women, offers analysis and recommendations to policy-makers, responds to media, and creates public education resources.

The Advisory Council has a legislated mandate to recommend legislation, policies, and practices to improve the status of women on Prince Edward Island.

- disability support payments – increases to ceilings across the board, more appropriate increments of funding, and indexing of payments to real costs of living.
- Call for a better appeals system, with representation external to government (such as community members with relevant experience and expertise).
 - Call for more overall funding to the Disability Supports program, with more equitable distribution of funding; elimination of criteria for including or excluding people from the program that create different “classes” of people.
 - Call for seniors with disabilities to be eligible for support.
 - Call for a provincial autism strategy.
 - Call for recognition of ongoing costs for items currently funded on a one-time-only basis.
 - Call for a new model for assisting Islanders to purchase prescription drugs.
 - Call for enhanced accessibility to support civic and democratic participation, including but not limited to voting.
 - Call for government and society to work together to reverse trends towards institutionalizing people, especially persons with intellectual disabilities.
 - Call for compassionate and people-centred systems, and for empathetic persons working within these systems.
 - Call for government to understand and implement principles and values that allow self-determination, choice, and rights for persons with disabilities, through person-centred plans that address individual needs.

We join our voices with those who have made these calls for action.

Other, wider issues that we heard voiced in presentations at the Disability Support Services Review connect directly with past and ongoing recommendations of the PEI Advisory Council on the Status of Women to improve the lives of women and girls. These systemic issues include the following:

- **Poverty:** Call for government to enact good policies based on justice and equity, and that recognize the rights of citizens — not hand-outs based on charity models.
- **Housing:** Call for investment in and planning for affordable housing, with universal and accessible design, with recognition of the gendered nature of housing (for instance, the safety needs of women leaving violent situations), and allowing choice of where to live and who to live with.
- **Transportation:** Call for Islandwide public transit that is physically accessible, paired with transportation programs for people with specific needs (such as persons with disabilities or seniors). The PEI Public Transit Coalition has commissioned a feasibility study for Islandwide public transit and will lobby for accessible transit.
- **Caregiving:** Call for recognition of the unpaid work of families (very often of women), to provide care, especially personal and emotional care, and to provide case management.
- **Safety:** Call for freedom from violence and fear of violence and abuse.

The particular, gender-based needs of women need to be taken into consideration by the Disability Support Program, especially on two fronts: 1) prevention of violence and abuse and 2) support for caregivers.

Why Disability Support Services Are a Women's Issue

Women with disabilities face double discrimination: discrimination on the basis of sex and on the basis of ability.

On Prince Edward Island (Statistics Canada, PALS 2006):

- Of Prince Edward Island females, 16.9% have a disability.
- Females make up 53.5% of Prince Edward Islanders with disabilities.
- Women in Canada are more likely than men to have a disability related to pain or mobility, in all age groups. The rates increase with age, but so does the gender gap. Across Canada, 79.0% of working-age women with disabilities reported pain-related limitations on their activities.
- There are more females than males with disabilities in every age category of Islanders, except ages 5 to 14. (This is a change since the 2001 PALS survey, when women outnumbered men in every age category. This change possibly reflects improved diagnosis of learning disabilities, which appear to be more prevalent in boys.)

In Canada and around the world, studies have shown that women with disabilities are more likely than most women and more likely than men with disabilities to experience violence and abuse. Some of the facts on women with disabilities are quite shocking, especially regarding family violence and sexual abuse and violence.

Statistics from the Government of Canada National Clearinghouse on Family Violence (2004) suggest the range of the problem:

- Up to 83% of women with disabilities will be sexually abused at some point in their lives.
- Between 40% and 70% of girls with intellectual disabilities will be sexually abused before adulthood.
- Women with disabilities who have experienced violence may face specific (physical or intellectual) barriers in calling the police or accessing services for abused women, including shelters.
- Women are frequently threatened with drastic consequences if they report or reveal abuse; women with some disabilities may not be able to evaluate these threats.

The kinds and effects of abuse against a woman with a disability on Prince Edward Island were dramatized in the film and the stage musical *Johnny Belinda* — a local story with global impact.

In addition, the *Journal of International Women's Studies* (4.1 November 2002) summarized:

- A 1989 study by DisAbled Women's Network (DAWN) Canada found that 40% of women with disabilities had experience abuse and 12% of women with disabilities had been raped.
- A 1991 study of women with disabilities, in which 82% of women reported experiences of abuse, the abuser was known to the victim 96% of the time. Women reported that 44% of the time, their abusers were service providers.

(*A note: It is also shocking that most of the studies on women with disabilities in Canada are so old, considering the severity of the problem suggested by ground-breaking studies twenty years ago.)

The 2001 PALS Survey data reveal the crushing poverty of Prince Edward Island women with disabilities, even compared with men with disabilities:

- PEI women with disabilities ages 15 to 64 had an average income of \$15,722 a year, only 65% of the average annual income of men with disabilities. (*The average annual income for men with disabilities in 2001 was actually higher than the census-reported provincial average income for 2000, when PEI incomes were lowest in the country, along with those of Newfoundland and Labrador.)
- Median income for PEI women 15 to 54 with disabilities was \$10,283, compared \$18,993 for men with disabilities.
- Social supports for senior women make a dent in the poverty: average income for women with disabilities over 65 was \$19,590 (85.6% of the average for men with disabilities of the same age, and their median income was \$14,631.
- Most PEI women with disabilities (65.3%) had income under \$15,000 or no income at all.

The economic and social status of women with disabilities create barriers to escaping violence and abuse.

VIOLENCE & ABUSE

Why the Prevalence of Family Violence against Women with Disabilities?

The DisAbled Women's Network (DAWN) reminds us that women with disabilities often must extend their idea of "family" — and their network of intimate, day-to-day relationships — to include caregivers and service providers who assist them in their everyday activities. Their "families" might include friends, neighbours, caregivers, medical professionals, or even disability support workers. Women who have grown up with disabilities are often taught to be compliant — even more compliant than most girls and women. They might already feel limited power to control their lives, leaving them more vulnerable to threats or coercion. They might be forced to live in unsafe housing or locations due to poverty or needs for accessibility features. They might be forced to live with people they do not choose to live with. Women with disabilities are often more limited to their homes, where violence and

abuse can occur within the “family” in private; they may be less able to find safety and security in public spaces. Isolation is both a risk factor for abuse and a tool abusers use to control women.

“Family” might look different for women with disabilities for other reasons. Recent focus groups with Atlantic Canadian seniors with disabilities by the Atlantic Seniors’ Housing Research Alliance spoke with 34 disabled seniors in 4 focus groups. (About three-quarters of participants were female.) The focus groups found that more disabled seniors compared to other seniors had never married (44%). More than a third of disabled seniors lived with non-family members, a larger percentage than other similar groups of seniors. Most (82%) said they lived alone or with just one other person. Also of note, the seniors with disabilities showed the highest proportion (53%) of any comparative group of low income — less than \$15,000 per year. They were more likely than any other group to talk about the direct cost of housing in their discussions.

Our discussions of family violence need to broaden the view of family and intimate relationships if we want to serve women with disabilities well, through prevention strategies and services. Focussing on spousal or intimate partner violence is important, but it is not sufficient to meet women with disabilities’ violence prevention needs.

Premier’s Action Committee on Family Violence Prevention

The PEI Advisory Council on the Status of Women has recommended that government renew the mandate of the Premier’s Action Committee on Family Violence Prevention as soon as possible, and the Premier and Minister Responsible for the Status of Women have indicated this will happen. **When the Premier’s Action Committee is reconstituted, we call on government to appoint a representative who can speak to the specific concerns of persons with disabilities, and especially of women with disabilities.** Preferably, this person would have direct experience of living with a disability.

It should be said that preventing family violence is also an important element of preventing disabilities. Brain injuries caused by child abuse such as shaken baby syndrome are a significant cause of preventable disability.

Woman Abuse Protocols

There are currently nine Woman Abuse Protocols that have been developed for financial assistance, hospital emergency, and several areas within justice. Only the Hospital protocols make any mention of abused women with disabilities. **The PEI Advisory Council on the Status of Women recommends funding to assess the need for new protocols to support women with disabilities.** In addition, we call on government to improve uptake of existing protocols and to improve their responsiveness to diversity groups. New funding is needed for an initiative to ensure Woman Abuse Protocols recognize varied abilities,

and/or to provide ongoing training for and application of protocols, including sensitivity training to heighten awareness of special needs of diversity groups, such as persons of varied ability.

Community Family Violence Services and Supports

Given the high level of vulnerability and high rates of violence and abuse against women with disabilities, **it is essential to support community services for women, such as Transition House Association and the Rape and Sexual Assault Crisis Centre, to be able to provide for these women's needs.** Barriers that prevent women from getting help apply doubly, or triply, to women with disabilities at every stage of their transition out of violence and into safety. Currently, Anderson House and second-stage housing each have only one accessible unit. The bigger problem they face, though, is helping women leaving violent situations find somewhere to go. There is so little affordable and accessible housing available, there is often nowhere to transition to safety. Once new shelter has been found, women with disabilities might need to find new caregivers for geographic, safety, or other reasons. They need to be support to get assistance in place efficiently, so they can resume their daily activities. Barriers to accessing outreach services and rape and sexual assault counselling and support vary by disability type. What we do know: there are women with disabilities who are in danger and who face multiple barriers to getting the help they need to find safety.

CAREGIVING

Supports for Caregivers

As your panel and government move forward to examine service delivery, we call on you to use gender-based analysis. That is, **we call on you to examine how policies related to caregiving may have different and unequal outcomes for women and men, based on the differences in their lives.** A gender lens will allow you to recommend policy that is non-discriminatory and supports women's equality in a society where women continue to bear a heavier burden of caregiving responsibilities.

Especially, it is important to consider how the Disability Support program reimburses "professional" caregivers compared to "family" caregivers who are supporting persons with disabilities. In 2005, Canadian women reported they continue to spend almost two (1.8) hours a day on average more than men doing unpaid work in the home, despite women's high workforce participation rates and increasing time in paid work (Statistics Canada, July 19, 2006). Taken over the course of a year, this means more than 650 more hours — over 16 forty-hour weeks — devoted by women than men to unpaid work. In many families, it continues to be primarily women who are expected to provide care to family members who are young, old, ill, or living with disability. When public policy pays for caregivers in institutional settings, but not in families, it may lead to unnecessary institutionalizations. But,

more importantly, it also reinforces the dangerous notion that unpaid caregiving is women's primary role and function in society. This leads to exhausted caregivers who also struggle against economic inequality (inability to accept full-time work, reduced immediate and pension income) and limited self-determination, choice, and freedom. Their unpaid work must be recognized, and the costs to their families and to their time must be accounted for. On the other hand, support to families should avoid creating new pressures on caregivers to leave the workforce or to give up their preferred activities to take on caregiving. **We ask you to undertake specific analysis of the costs and benefits of providing direct financial assistance to family caregivers, with attention to what outcomes would best support women's equality and choice.**

A related issue is examining the value the Disability Support program places on emotional and personal care, compared to medical care. This is particularly important where families are caring for people with intellectual disabilities. If the only funding available is for medical care, this could very well increase the tendency to medicalize problems that could be dealt with better by supporting emotional and personal care. Medicalization of disabilities may contribute to institutionalizations that are costly in terms of both money and human potential. Emotional and personal care are often provided by women and are undervalued both in terms of funding for this care from government programs and in terms of wages and benefits for service providers. Statistics Canada reports an average Canadian wage of \$24.71/hour for ambulatory health care (doctors', dentists, and specialists' offices) and hospital health care services, compared to \$17.55/hour for nursing and residential care and social assistance (Statistics Canada, 2007). While each category captures a wide range of services, the average wages for nursing, residential, and social assistance services are still just 71% of the wages for doctors' and hospitals' services — and this figure does not take into consideration unpaid work at all. **We ask you to undertake specific analysis of the costs and benefits of providing more support for personal and emotional care, with consideration of the need to provide livable incomes for providers of personal and emotional care.**

Respite is essential for caregivers, whether male or female, paid or unpaid. In some cases, respite might be a prevention measure that reduces risk factors for violence or abuse. **We ask you to call for an assessment of current and future training and funding needs for respite workers.**

Persons with Disabilities as Caregivers

While we have dedicated several paragraphs to caregivers of persons with disabilities, we also want to acknowledge the need for support for caregivers with disabilities. The DisAbled Women's Network (DAWN) Canada has found that services and supports for pregnant women or mothers with disabilities are inadequate, when they exist at all.

Women with varied abilities are sometimes called on to care for other members of their

family. Women with varied abilities sometimes are or become mothers themselves. They must have the same reproductive rights as all women: the right to their sexuality and sexual orientation and its full expression; the right to refuse rape, abuse, and exploitation; the right to accept or defy conventional morality; the right to control their fertility; the right to choose whether or not to continue a pregnancy; and the right to build their families by birth or adoption. A woman's need for some assistance in some aspects of daily living or for financial support to compensate for varied abilities must not in any way compromise her right to choose. **If the Disability Support program or other services are called on to offer additional supports for caregivers with disabilities, then they must do so to whatever extent is needed to support her choices.**

GENERAL

Partnerships with Non-Governmental Organizations

The backgrounder to the current review reflects that “\$5.47 million dollars is provided in annual grants to 17 community-based organizations who serve Islanders with physical, intellectual and developmental disabilities.” This includes groups and agencies that provide direct services and supports and that offer important advocacy. In our experience, non-governmental organizations are frequently able to provide tremendous care, including social and emotional support and advocacy, provided they are funded fairly and equitably.

A warning: Despite the urgent need for funds for the drugs, basic living costs, and educational supports that persons with disabilities require, increases must not come at the cost of budget cuts to the NGOs/voluntary sector. Community groups provide support and develop knowledge that is invaluable and irreplaceable. They strive to work inclusively and to give complex problems a human dimension and people-based solutions. Discussion at the public consultation we attended suggests that government may need to work harder to help communicate the richness and value of NGO contributions to the lives of persons with disabilities. The pie chart in the backgrounder and the chart listing community organizations do not capture the true value of the province's \$5.47 million dollar contribution to these groups and their varied services.

In our view, one of the greatest opportunities for enhancing disability services is an enhanced role for well-supported community organizations fulfilling a variety of roles and needs.

A good resource for looking at the community sector's role is the new report, “Bridging Public Investment and Social Value: An examination of the supports for the Social Economy on Prince Edward Island,” by Barbara Groome-Wynne, published by the Institute of Island Studies at UPEI, as part of the Social Economy and Sustainability Research Network.

Ratification of the Convention on the Rights of Persons with Disabilities

In the past weeks, we have had the privilege of meeting with provincial and federal officials regarding Canada's potential ratification of the *Convention on the Rights of Persons with Disabilities*. **The PEI Advisory Council on the Status of Women supports Canada's full and unreserved ratification of this treaty.** We suggest that your panel's report would do well to include a recommendation to support Canada's ratification of the treaty by spring 2009. When it comes into force, the *Convention on the Rights of Persons with Disabilities* will send a powerful message to the world about our shared expectations that persons with disabilities should be supported to participate fully in our society and in all societies around the world. The treaty will provide a valuable tool under international law for advocates who are pressing for respect, rights, and services for persons with disabilities.

Conclusion: Rejection of Paternalism

Several presenters to the Disability Support Services Review called for compassion and for an end to paternalistic attitudes implicit — or explicit — in policy or practice. In our view, much “paternalism” stems from patriarchy. Gender-based analysis can inform policy development in positive ways to counteract effects of gender inequality. Applying a gender lens alongside a disability lens in assessing the policies and practices of the Disability Support Services and programs will absolutely assist in setting a course towards more sensitive policy to address the complex needs of complex individuals in a flexible and responsive manner.

Thank you for the opportunity to provide suggestions to the Disability Support Services Review. We very much appreciate all the panel members who have contributed their time and their knowledge to this review process. Good luck with your deliberations. We look forward to your report and recommendations and to the policies that result from them.

Sincerely,



Isabelle Christian
Chairperson

CC: Hon. Valerie Docherty, Minister Responsible for the Status of Women
Michelle Harris-Genge, Interministerial Women's Secretariat
Members of the PEI Advisory Council on the Status of Women