

# Housing Realities and Requirements for Women Living with Disabilities In the Capital Region of British Columbia

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January 2004, Women's Housing Action Team, Victoria BC

Over 21,000 women lived in low income households in the Victoria Capital Region and spent 30% of their income on shelter according to the authors of the report, "Housing Policy Options for Women Living in Urban Poverty: An Action Research Project in Three Canadian Cities"<sup>2</sup> published in 2001. There is, however, little information on the housing situations or perceptions of women themselves who are living with disabilities. A research study<sup>3</sup> by the Women's Housing Action Team<sup>4</sup> was conducted in 2003 to help redress this gap. This short report offers a commentary on the magnitude of concerns and a summary of housing realities and requirements identified by a diverse group of women living with visible and invisible physical disabilities in the Capital Regional District of British Columbia.

## Magnitude of the Problem

In 2001, 3.6 million Canadians, or 12.4% of the population, reported having disabilities that limited or reduced their everyday activities.<sup>5</sup> Looking only at women between the ages 45 to 64, the percentage is higher at 17.5%. Translating this percent into number of women means that there are over 6,000<sup>6</sup> women in the Capital Regional District who report significant limitations.

Most women identify disabilities due to chronic pain or/and mobility difficulties as limiting their capacity to walk, climb stairs, carry an object for a short distance, stand in line for 20 minutes, move from one room to another, get dressed or cut food. Less frequent, but still significant, are disabilities of hearing, sight, speech, as well as invisible limitations posed by learning disabilities, developmental, psychological, or memory problems, and chronic fatigue.

Additionally relevant for planning appropriate housing is that four-fifths of the respondents lived with two or more different types of disabilities. In addition, over 40% reported severe to very severe limitations, estimated to be 2,400 women in the Capital Region. Two-thirds of respondents in this random survey of Canadians who identified as living with disabilities stated that they needed assistive devices or help with everyday activities. The majority who needed help reported they received it in 2001, although a significant minority of nearly one-third needed more equipment and assistance, which they could not purchase due to costs, unavailability of help required, or inadequate public services or insurance plans. As for housing, one-third reported a need for, but did not have, adequate modifications. Those over 65 years reported more satisfaction and access to modified or assisted housing than those under 65.<sup>7</sup>

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## The Housing Realities of Women Living with Disabilities

The numbers indicate the size of the problem. Yet to create appropriate housing policy, practice and stock, it is essential to understand the housing realities of women living with disabilities, and what they say they require.

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There is considerable diversity in this study's focussed conversations with women about their experiences, needs, and concerns. Some women are renters, others owners. Some live on very low and precarious incomes, while others have more "adequate" and steady incomes. Some live downtown, others in the western communities. Some of the women live with visible disabilities, needing wheelchairs, walkers, hearing dogs, or attendants. Others cope with invisible disabilities such as chronic fatigue and arthritis. While there is such diversity in experiences, needs and concerns for women living with disabilities, some realities are common to most of the women in this study.

### 1. Women Experience Significant Difficulties Finding Affordable, Safe and Suitable Housing

The first reality is the many, persistent, and intense difficulties women living with visible and invisible disabilities face in finding and keeping housing that is affordable, safe, and suitable. As one woman, who was still looking for housing at the time of the study, stated:

*I don't know how much time and effort I've put into trying to find a way to make it work, of finding affordable housing. And that's what I get sick of. I'm a pretty creative person and you have to be when you're on a limited income. You find ways to make things work; you find ways to stretch those dollars. But I just can't seem to make that one part work. I can't find affordable housing for me.*

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The problem of affordable housing throughout the Capital Region is well documented. A recent report commissioned by the Capital Regional District to develop a Regional Housing Affordability Strategy states that this "region is one of the most expensive and least affordable housing markets in Canada"<sup>8</sup>

Other participants commented that the daily work of living with disabilities becomes even more difficult if one is not living in a place that "is your home" that "nourishes my soul." It is difficult if, "constantly, somebody is watching over you." There are also difficulties of keeping a private, safe home if there are too few people or services to assist when necessary. One homeowner whose disabilities are worsening concluded: "The upkeep is too much for my energy and that's a constant challenge. And those will be reasons that I will have to leave, because I just won't be able to do that anymore".

## 2. Regular Assistance is Required to Keep Housing

The second reality is that women living with disabilities require regular assistance and advocacy resources to ensure suitability, safety, and affordability in housing. As one woman said, “coming down with blindness is another story, if I didn’t have assistance then I don’t know where I would be today.”

Assistance and advocacy are not “extras” but essentials, not “favours” but requirements. Women with disabilities do not want “to depend on others for the basics in your life...on the good will and favours of other people,” and yet assistance is often essential. Choosing who to “depend”<sup>9</sup> on, and in what way, is also crucial. Choice then is a right and requirement of assistance.

Advocacy is also essential so women are not forced to accept a house because of its affordability rather than its suitability to life with disabilities. For instance, women made it clear that life with arthritis can make it impossible to do “laundry down six flights of stairs” or “washing stooped over the bathtub.” Others need home support, or live-in attendants or animals. It requires advocacy to find and keep assistance and individuals that “you can trust who are not going to take advantage of the situation. So you are not feeling like you are being violated when they are in the house.”

## 3. Living with Disabilities Often Means Living with an Insecure Future

The third reality is that even if women living with disabilities are currently residing in adequate, safe, and suitable housing of their choice, the intense concern about an insecure future is constant and deep. The worry in the following quote was echoed throughout the conversations.

*I feel like I’m lucky that I have a roof over my head....well I’m constantly at risk of losing it. So I think that even just that concept that I can have more than just the basics, that it can be bright, that it can be warm, that I can have my pets, that I can afford it, that it’s not going to be pulled out from under me.*

Losing “it” can mean losing housing, money, health, and assistance. There are concerns about what happens if and when health deteriorates, or home support hours are cut, or rent is increased, or the landlord changes. Women living with disabilities struggle with the unknown implications of fluctuations in their illness, capacities and requirements. They also struggle with a keen sense that their entitlement to their housing requirements are increasingly tenuous in times of cuts to public services, pressures for everyone to find gainful employment, and expectations that housing markets be profitable. It is the fear of the “hammer falling” that weaves through the conversations. As one woman states: “I don’t think you have lives. You exist; you don’t live. We are waiting for the next hammer to fall.”

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#### 4. Living with Disabilities Often Involves Crazy-making Contradictions

The fourth important reality is the “crazy-making” contradictions that women living with disabilities face. Women state that choice in housing is important for one’s health and independence. But choice quickly becomes tied up in conditions. Choice may be considered essential and desirable but, for women living with disabilities, that choice is conditional, tightly tied to worthiness, established not by oneself but by others who evaluate a woman’s connections to money, paid work, family, and volunteer contributions. If one is evaluated by others to be less worthy, then one becomes less free to choose what is desired or needed in housing.

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Women living with disabilities desire independence and yet they are constantly reminded of their “dependence.” They are supposed to squeeze themselves into having “thin not thick needs.” They are expected to manage or cope, accept assistance with gratitude and to not demand it. This expectation to squeeze one’s life into a small box is captured by one participant who says:

*You’re supposed to get rid of it all, and somehow you’re not supposed to have a life. You cease to be an individual with interests. Not wanting things....furniture, artwork, pictures of your kids. So your life is supposed to go down the toilet.*

All the participants in the research spoke of their work in paid jobs, in contributing to community, in helping each other do housework, and in caring for friends. Yet, a huge chunk of time is taken up in “maintenance or sickness work”: taking care of themselves to ensure they can make their own choices. There are other barriers to making contributions and other contradictory situations that make it difficult to participate in life. These include hurtful, inaccurate comments of others. One woman said: “If they see you walk to the mail-box one day they say, ‘Well, why aren’t you working? You can walk.’ To have people who really understand, there are good days and bad days, there are financial crises.” Common throughout the findings is a sense that others had inaccurate perceptions about what the daily requirements are for living with disabilities, what contributions these women make, and what services exist. Concluded one participant:

*“And I am cursed with relatives who think there are these wonderful places out there for people just like me and the government will take care of us there.”*

*And I am cursed with relatives who think there are all these wonderful places out there for people just like me and the government will take care of us there. You just have to tell the government what you need and they’ll put you into one of those nice places where everyone looks after you. And these people sincerely believe that it exists out there in whatever world they’re living in. The same world where they think that social services gives you everything you need.*

Participants spoke of the forced choices that pit independence against health. Sometimes they are not able to find adequate housing and are forced to share with someone who is not a “match” in order to pay the rent. But sharing can make their health worse, and therefore they are less able to look for work.

*I’m probably going to be cutting off my phone and I have had a car on the road. I’ll be taking my car off the road this month....When I was working the plan was to first of all be able to buy things like shoes that I haven’t been able to buy in years...to save some money so that I could work towards self-employment, but that’s gone down the tube now. The money that I had, I’ve been living on for the last month.*

Much time and energy are required to manage feelings and perceptions of themselves, as well as others’ perceptions of them. For instance, wanting to feel lucky yet feeling annoyed that gratitude is expected. They express anger, sadness, and puzzlement that they are supposed to feel grateful, or that they feel greedy. They wonder if they have the right to expect access to improved living conditions, which most people take for granted. Says one participant: “...my rent of \$480 does not include heat and hydro...I need more money to stay in my current situation, as greedy as it may sound.” A common worry is that if they are not sufficiently grateful, or are too demanding, they will lose their housing, their reputation, and possibly their claims on some services:

*But there’s something wrong with thanking God that you’re on disability, so you can get into subsidized housing, so that you can afford to buy food, that you’re grateful for these crumbs and dregs that society will throw at you to shut the f. up.*

## **5. Women Have a Diversity of Housing Requirements**

Finally, there is the reality of diversity. Besides affordability and safety, few women share all of the same specific requirements or wants. Their disabilities are different, as are the ways they manage and cope with their capacities and limitations, contradictions and insecurities; and some may have more than one disability. It is the diversity that has significant implications for the development of affordable, safe and suitable housing in which women living with disabilities can be supported to live.

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## Housing Requirements for Women Living with Disabilities

The identified complications, contradictions and diversity of the realities of the lives of women living with disabilities poses obvious challenges to establishing housing that meets these women's needs. This report summarizes requirements identified by the women who participated in the focussed discussions.

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### **1. Women Require a Home that is Affordable for the Realities of Living with Disabilities**

Affordability is not just the cost of the housing, it includes the costs that are required to live with disabilities. Hand railings, lifts, attendants, wheelchairs, and heat are not extras but requirements, as is the money needed to pay for them. As one woman said, "The cost of medical. . . is one of my big issues now that I have exorbitant medical costs and no coverage." In speaking about the cost for her accommodation, one woman revealed that the financial limits within which she lives, "means that in the winter time the thermostat does not go above 62 degrees."

### **2. A Home that Provides Safety for the Realities of Living with Disabilities**

Women are very specific about the ways in which they are unsafe. For instance, they need to live free of physical and emotional harm both within their homes and in the community. Women with disabilities are less able to defend themselves from physical attack and structural inadequacies can interfere with their ability to exit their home in an emergency. Women require homes within which they can move safely. They need to be able to live with whom they choose, rather than out of financial or physical need. Insufficient income to cover living costs can result in "undesirable" living choices. Similarly required is the choice about how and from whom they receive assistance, especially when accessing home support.

### **3. Women Require a Home that is Adequate and Customized to Meet Their Basic Needs**

Having a home means having a basic place to live that has a roof, heat, clean water, clean air, is dry and sound proof. As one woman describes, "where I can take care of my basic needs like having a bath, sleep, or whatever." Additionally, many women spoke of structurally unsound, cramped, or otherwise inadequate space in which to move, do required exercises, entertain company, or do work. One woman spoke of her small place: "The amount of floor space that is uncovered, that you could stand without touching anything, is less than a normal person's bathroom. I don't call that living...I can't find a place that is not going to be as bad or worse."

*Women require homes within which they can move safely.*

It is a requirement for some women to have hand railings on stairs and in bathrooms, or to have stoves and fridges they can reach if in wheelchairs. To many this means a place that facilitates independence; where a woman can do as much as possible for herself.

#### **4. Women Require Living Choices that Facilitate Healthy Living**

In addition to requiring privacy and a place of sanctuary, women clarified that they require a home in which they have choices about what is valuable. This can refer to having or not having pets, a backyard, enough space inside to move around, natural light, space for hobbies, for earning income, for doing home rehabilitative exercises, or being able to make sounds. Women require living conditions that foster a sense of power and that support their capacity to take care of their housing in terms of how and from whom they receive support, as well as their participation in community.

#### **5. People that Assist and Advocate for the Realities of Living with Disabilities**

Many women identified barriers to obtaining housing and supportive services, due to either physically being unable to access services or because of the complicated or restrictive nature of policies. One woman offered the following: "Have independent people you can go to and say something is not right here. And your concerns are being listened to instead of being shuffled to the bottom of the deck".

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## Concluding Comments

*Disability is not generic. Housing solutions, therefore, cannot be generic.*

There are thousands of women between the ages of 45 to 64 living with disabilities in this region, many living with serious limitations. The discussions with the women who participated in these focus groups clarify that, although the realities of living with disabilities are diverse, they need to be considered in relation to each other. Housing requirements cannot be separated from the person.

Housing solutions need to be flexible and individualized: one approach does not meet all requirements nor does “one size fit all.” Flexibility is essential in all policy and planning. Disability is not generic. Housing solutions, therefore, cannot be generic.

Women living with disabilities require the assistance and advocacy associated with finding and keeping housing that is affordable, safe, and suitable to their diverse needs. This means rights. The essential rights that women speak of are:

- **The right to the housing requirements that are relevant to the realities of living with disabilities**
- **The right to dignity, privacy, safety and independence**
- **The right to engage as full citizens in accordance with their abilities and disabilities**

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*I get the feeling that somehow we’ve taken housing separate from every thing else in our lives. That’s crazy-making for me. I think- all I want is to be as independent as possible. I’m not allowed to be...I’m back at that place of trying to get ready to work again...it’s not separate from this stuff. We strive for something in our lives- being a good mom, an artist, helping out in the community. It’s integral to our health.*

## End Notes

- 1 Special Acknowledgement goes first and primarily to the women who participated in this research. That authors would also like to acknowledge the Research & Policy Circle of the Women's Housing Action Team who assisted at all stages of this process, and Status of Women Canada for funding the Women's Housing Action Team.
- 2 See M. Reitsma-Street, J. Schofield, B. Lund & C. Kasting. 2001. *Housing Policy Options for Women Living in Urban Poverty: An Action Research Project in Three Canadian Cities*. Ottawa: Status of Women Canada.
- 3 During the summer of 2003, fifty email and poster invitations were distributed plus follow up with phone calls and personal invitations to various persons and groups who know women living with disabilities. Thirteen women with invisible and visible disabilities consented to participate in taped focus groups, one held in Victoria and the other in an outlying community. Two women who were unable to attend the groups answered the five focus group questions electronically. Several of the women also contributed to an analytic session examining the data and gaps. The three sessions were co-facilitated; one of the facilitators was a staff person of WHAT, and the other was a woman currently living with a visible disability who received an honorarium for her work. Contact Heather Gropp at Women's Housing Action Team for more information on research process, sampling, questions, and analytic processes.
- 4 Women's Housing Action Team (WHAT) is a group of women with expertise and interest in creating affordable, safe, innovative housing options for older women (40-55 years) and for ensuring that housing policies include women.
- 5 Cossette, L. and Duclos, E. 2002. *A Profile of Disability in Canada, 2001*. (No. 89-577-XIE) Ottawa: Statistics Canada.
- 6 Exact figures in 1996 for Capital Regional District are 17.5% of 21,350 women ages 45-54 equals 3736, plus 17.5% of 13,955 equals 2442 for a total of 6,178 using M. Reitsma-Street, A. Hopper & J. Seright (Eds) *Poverty and Inequality in the Capital Region of B.C.*, University of Victoria, April 2000, p. 72 .
- 7 Duclos, E. and Langlois, R. 2002. *Disability Supports in Canada, 2001*. (No. 89-580-XIE) Ottawa: Statistics Canada.
- 8 *Building Our Future: CRD Housing Affordability Strategy* . Final Consultant's Report July 2003. A Proposed Housing Affordability Strategy for the Capital Region: For Review and Discussion. CRD Regional Planning Services, Victoria B.C. pg. 7.
- 9 The word depend is in quotations because the intention is to refer to the frustrations of requiring assistance, support and advocacy as a result of living with disabilities while wanting to be able to live without requiring such assistance, support or advocacy. This point will be discussed later in the report.