

Dear Minister Simpson,

Thank you for your commitment in developing accessibility legislation and for inviting feedback. The Framework for Accessibility Legislation is an excellent plan to help people with disabilities participate in a full, equal and meaningful life. I strongly believe, as someone who works with people who have Huntington's disease (HD) and their families, that home support is not meeting their needs or the needs of those with other neurological diseases such as dementia.

As many people with HD are between the ages of 35 to 55, a large portion of the health programs, especially home support, do not assist with the challenges they face. They often need help with cleaning, cooking, laundry and other activities of daily living. Unfortunately, home support does not provide these essential services and people with HD do not meet the criteria for programs that do offer these services, such as Better at Home, because of their age. Due to the early onset of this disease, many are unable to work and they cannot afford to pay privately for these services.

A common challenge for families of people with HD is having their loved one not meet the home health criteria as they do not need bathing, personal care and/or medication assistance. Families have shared that when they get home at the end of the day, their spouse or adult son or daughter has not eaten all day because a lack of initiation and apathy is a part of HD. I have heard about them coming home to flooded kitchens or that their loved one has wandered out of the house. Having someone do a short visit during the day to ensure the person with HD is not at risk and has had a meal is essential.

Unfortunately, when home support has been involved families report the revolving door of care aids has created anxiety and confusion for the person with HD and has led to the person not cooperating with the care being offered or refusing it completely. People with neurological diseases need to see a familiar face and develop a relationship with the person, which means only having a few care aids coming into their home allowing more time for care to be done.

A person with HD in the early to intermediate stages may experience anxiety, depression, changes in behavior and changes in how they think. Because HD is considered a health problem, they rarely qualify for Mental Health services. When a mental health team in the community has followed people with HD, they are able to remain longer at home and have a better quality of life.

Finally, our interdisciplinary team at the Centre for Brain Health - consisting of a neurologist, psychiatrist and social worker - complete assessments that include psychosocial aspects, health and mental health needs and risk factors specific to HD. Our assessments could be an integral part of the home support assessment, but are not being used as home health only use their own assessment tool that does not seem to capture the needs of those with neurological disorders, and in particular HD, which is like a combination of ALS, Alzheimer's and Parkinson's.

Thank you again for seeking out feedback regarding those most affected by disabilities and please do not hesitate to contact me if you require any further information or have any questions.

Respectfully submitted,

*Rhonda Romolock, BSW RSW
Director, British Columbia Resource Centre
Huntington Society of Canada*

Centre for HD, UBC Hospital, S179
2211 Wesbrook Mall
Vancouver BC V6T 2B5

Telephone: 604-822-7195
Email: rromolock@huntingtonsociety.ca
BC Resource Center: 604-822-7195
CHD Website: www.chd.med.ubc.ca
www.huntingtonsociety.ca

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