The Quesnel Multiple Sclerosis Self-Help group met on

March 7, 2014 to discuss the WHITE PAPER ON DISABILITIES

The following is our input:

INNOVATION

TOPICS:

PARTICIPATION

MEMBERS OF THE QUESNEL MULTIPLE SCLEROSIS SELF-HELP GROUP

QUESNEL SPINAL CORD MEMBER

SOLUTIONS: Combining our resources. I was glad to have a member of the spinal group attend our Quesnel MS Self-Help group meeting as we are able to join forces in helping to make people’s lives with disabilities easier. We are grateful to have this opportunity to be involved in this white paper.

CHOICES

PERSONAL SUPPORTS

TOPICS:

HOME CARE

* Supportive husbands, wives, children, relatives and friends are very helpful, however, unfortunately there are those with disabilities in the community that do not have this advantage
* There is a variety of prices ranging from $20.00 to $28.00 an hour for private care. Many people with disabilities are unable to afford private care as they are dependent on Social Services.
* Funding needs to be re-instated for provincial home care.
* Home support based on last couple of years taxes -With the provincial Home care support, the aides do not do housework. People with Disabilities need help with housework
* WE CARE - $25.00 care aid $27.00 RN
* $55.00 LPN $45.00. Foot care in office $35.00 ln home $40. Once again those on social services cannot afford this kind of care.
* We would like to see that services that are offered to seniors would also be available for people with disabilities

**WORK & CONTRIBUTION**

Reduce barriers - to make it easier for people with disabilities to work or contribute to the community. People with MS often don't tell their employers of their disease for fear of being laid off. lf there was an initiative for employer/government cost sharing of medical, dental and sick leave coverage for part-time employees whose contribution to the work force is limited by disability, employers may be more accepting. Another idea would be to have an agreement of understanding made between the employer and disabled employee of number of hours contributed per week or month, offering a flexible work day or work week outlined by the employees capabilities. An extra room for personnel privacy for care needs or rest breaks would be helpful to support those employees.

Many of us with disabilities will work as volunteers as we want to put our skills to work and also give back to the community.

ASSISTIVE TECHNOLOGY

* An organization that will customize vehicles at no cost
* Access to cost efficient computer technology

AIDS AND DEVICES

Red cross loan cupboard eg. shower bench and walker

Have to pay for installations of grab bars and home renos

Often people are not aware of the HAFI or RAP grants or do not know how to go about filling out the forms

ACCESSIBILITY

Cutcurbs? bathrooms?

Quesnel is continually working to improve our city's accessibility.

We need doctor's offices that are accessible with lifts for the examining tables.

We need accessible washrooms in shopping areas that are open all week.

UNIVERSAL DESIGN BUILT ENVIROMENT

We need housing and care for younger people who are disabled, as living in senior's homes is not an ideal place.

Contractors who are experienced in building for disabled people to install ramps and other aids in homes.

HOUSING

The cost of rent for apartments is higher than the allotted amount for people on Social Services. This fact makes it hard for people on disabilities to ensure they have proper nutrition.

SOCIAL NETWORK

TOPICS

TRANSPORTATION

HandiDART in Quesnel is available but has limited hours during the week and none on weekends.

A wheelchair accessible taxi that is subsidized would be ideal so clients can go out on weekends.

COMMUNITY

Better at home, is this service just for seniors or can disabled call on their services too?

Peer counseling - our MS self-help group - network.

Spinal cord association has a peer counseling and support in B.C.

For those of us with MS, we are fortunate as we have the MS Society to call on for assistance.

Not all disabled people have that resource

INCLUSION

FAMILY

Supportive spouses, children, relatives and friends are not always the norm for some disabled people.

It is very important for caregivers to have resources that they can call on,as caring for loved ones can often be strenuous

INCOME

TOPICS

RDSP

We would like to see this extended up to 65 years of age.

SECURITY

For people on social assistance, there is no such thing as security. They are at the mercy of landlords that charge more than their allotment for rent. There is no way they can put money aside for a rainy day.

FINANCIAL LITERACY

Often those who are faced with a disability are not aware of all the resources for financial aid. Filling out forms and going from one agency to the next can be complicated and stressful. Having a social services agency set up for persons with disability - with personnel that are well versed in what services, devices, transportation, volunteerism, socializing, and financial options etc. may be helpful for persons with disabilities and their caregivers.

DISABILITY PENSION

Once again, an agency set up to help us jump through the hoops of obtaining what we are entitled to, would be very helpful.

On behalf of the Quesnel Multiple Sclerosis group, I am submitting our discussion on this important topic. I am including one of our members, Suzan Campbell, own thoughts that she has typed up. Some of her ideas I have inserted into our general report. Thank you for inviting us into the conversation.

Sincerely,

Donna Jagusch