

PATHWAYS TO INDEPENDENCE

PATHWAYS LEADERSHIP GROUPS

As a group of peers, Pathways has come a long way in forging a solid group of participants who share common concerns, goals and challenges and we've identified many issues that should be put forward to policymakers; issues that impact the lives of people with disabilities every day.

The idea of having Leadership groups has come from the peers who wish to address various topics by way of different advocacy methods.

The goal of the leadership groups is to bring together small groups of peers who would like to focus on common concerns and who are able to devote the time needed to work on the topic.

Participation would require a couple of hours a month, with zoom meetings outside of the main Pathways Peer Group. The groups would be supported by the Individualized Funding Resource Centre (IFRC) Society and Technology For Living (TFL).

Pathways To Independence Peers held a brainstorm discussion on the topics of interest, and these are the topic areas that they came up with:

1. Home Support Hours and Re-evaluating the Time Task Analysis (TTA)

- a. Hours should be based on individual circumstances and how they fit around activities and routines
- b. The Health Authorities don't provide CSIL Employers with hours for activities out in the community, for school, employment or volunteering etc.
 - i. Most of us are stretching our hours so that we can go out and have meaningful participation in the community
 - ii. People with physical disabilities deserve the support to participate in community
- c. Is there is a way that we could start working with the Ministry of Health around Community Involvement and Community Inclusion?
 - i. Persons with Developmental disabilities, who have CLBC funding, have a component to have community inclusion and have dollars to allocate towards being able to participate in the community.
 - ii. Physical personal care, either through agencies or through the CSIL Program, is hardly being met as it is, but the Community Component is critical and should be a part of independent living

- iii. A committee can focus on what the allowable support should be considered for people with disabilities and/or seniors, with the focus to change it.
- d. Some Health Authorities allow activities such as physiotherapy and swimming, but in other Health Authorities they are not. Expanding what would be considered the allowable hours to be part of the assessment process should be standard, and consistent, across the province.
- e. Participating in the community is at the core of why CSIL was formed, to promote independence and community inclusion
- f. Peers believe that the Ministry of Health should be providing funding for community inclusion hours, because we deserve to be involved in the community, and not be trapped at home.
 - i. CSIL employers work, go to school, employment and volunteer and enjoy socializing and without support many are unable to attend these activities
- g. Re-evaluating and overhauling the Time Task Analysis is needed to realistically determine what is allowable tasks and what are reasonable amounts of time for a task
 - i. Too many people are forced to stretch their hours for care or do without
- h. Implement all inclusive care hours so that people can remain in their homes, receiving,
 - i. Housekeeping Services
 - ii. Healthy Meal Preparation
 - iii. Adequate showers; daily if basic care if chosen

2. Home Support Hours for Seniors:

- a. Seniors and people with a wide range of disabilities require home support that will meet all their needs.
 - i. They are facing hurdles getting onto the CSIL program
 - ii. Some seniors have onset dementia, mobility and health issues and basic home support does not meet their needs
 - iii. This is about supporting one another and connecting Seniors and their families as a voice

3. The Disincentives for Couples, for People with Disabilities:

- a. Review and change of policy related to the issues related to marriage, insofar that the system determines that if you marry or cohabit with your partner, your spouse/partner is assumed to physically work to support your care needs and the Health Authority provides fewer hours as a result
- b. Family members, spouses should not be the default caregivers
- c. This is preventing people from marrying or living with a partner
- d. This decision by governments impacts the rights of individuals
 - i. People are losing tax benefits
 - ii. Policies obstruct PWD benefits when married
 - iii. This is a Human Rights Issue

4. Transportation Committee:

- a. Address the transportation issues for PWD with city councils
- b. Common issues throughout the province related to transportation
- c. Flight Travel
 - i. Accommodating wheelchair use for the flight
 - ii. Safety and lack of Airline training

5. CSIL Expense Guidelines:

- a. Form a group to review the guidelines to further expand expenses which will support staff retention
- b. As long as you remain within the funding limits, CSIL Employers should be allowed to expense reasonable incidentals;
 - i. i.e. Emergency caregivers call out; taxi fare should be an allowable expense
 - ii. i.e. Christmas bonuses should be an allowable expense
- c. Respect to payment to family members
- d. Review other expense guidelines that need to be updated

6. Volunteerism - CSIL Application Peer Support:

- a. Some peers would like to be on the CSIL program, but do not have family or friends who can support necessary components of their applications.
- b. This may be an opportunity for experienced CSIL employers to help others succeed on the program
- c. Some Health Authorities are requiring certain individuals with disabilities to have Representation Agreements in place as part of their CSIL application. Unfortunately, some people with disabilities who, for a variety of reasons, have no family or friends to participate in this responsibility
- d. Team Brainstorming leads to solutions

7. Public Awareness and Political Advocacy

a. Media relations:

- i. Thinking about promoting through video, radio and TV interviews
- ii. There are many different approaches to taking a video.
 - 1. Promoting CSIL as an alternative to home support agencies in a positive way, as making a difference to our lives and how it enriches our lives and the people we encounter
 - 2. As CSIL Employers we are making it possible to employ people and help local economy
 - 3. Generates taxes
 - 4. An alternative approach would bring up issues to the public

b. MLA campaigning:

- i. Start an MLA campaign to educate the MLAs of BC on the current issues facing their constituents with disabilities
- ii. This could focus on the CSIL program, or other issues that affect our community

8. CSIL Provincial Representation

a. Representation of CSIL Employers from each of the Health Authorities:

- i. Having 2 or 3 people from each Health Authorities on a committee to talk about the CSIL Program that can provide feedback and information not just back to Pathways but to the Association of CSIL Employers Executive so decisions can be made on how best to address the matters.
- ii. This will provide a full provincial perspective

b. Separate Committees from different Health Authorities:

- i. i.e. individuals who fall under Island Health can get together to talk about what is happening in this health authority when it comes to the CSIL program or other Home Support issues.
- ii. Relate the issues back for discussion and action

9. Client Contribution / Per Diem:

- a. Many people who receive home support also are required to pay a client contribution. How the Health Authorities determine how much an individual must contribute is unfairly designed and prejudiced against people who are not employed but have invested income.
- b. For many on limited funding, are unemployed are experiencing hardship with invested personal monies.
 - i. I.e. as provided by the peer: RRSP withdrawals are treated as income - it's a form of double taxation (\$5200 of every \$10k you withdraw is taken in increased care costs, meaning you have to draw out double to get the \$\$\$ you actually need, compared to a non-disabled person)
- c. There was significant advocacy for a cap of \$300/month for someone who is employed, however, many feel strongly that there should not be a contribution for basic support
- d. Other topics to be raised with policymakers
 - i. The lack of payment exemption is for people on CPPD only
 - ii. These are typically people who have acquired disabilities. They have worked so claim CPPD, but their CPPD is greater than PWD benefit, so they don't apply for that.
 - iii. An ICBC injury settlement is viewed as a replacement for funding by the Health Authority
 1. These funds are limited and expecting individuals to deplete these funds for home care, leaves them with nothing for their housing, income replacement or medical expenses etc.
- e. Using one's own money from an RRSP, from working or inheritance, and if they own a home, they wind up cash poor.
- f. A Pathways peer has begun to work on the following issues. She welcomes support from interested peers.
- g. Her focus topics impact people with disabilities across the province, and she hopes that her efforts will result in a deep systemic change.

These are voluntary roles. We value and respect everyone for their knowledge, abilities and for the skills of leadership and for those who just want to be more involved to support community.

Ruth Marzetti of Technology For Living and Paul Gauthier of Individualized Funding Resource Centre Society will provide support to the teams as these projects move forward.

If you are interested in becoming involved in groups supporting any of the topics, or have questions, please contact Paul Gauthier at paul@ifrcsociety.org