

PATHWAYS TO INDEPENDENCE

OCTOBER 27TH, 2020, 1:30PM TO 3:30PM

ZOOM VIRTUAL CONFERENCING MEETING NOTES

Hosted By:

Paul Gauthier

Individualized Funding Resource Centre Society

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Technology For Living

Guest Speakers:

Ean Price for WE TALK TECH

Elizabeth Straus, PhD Candidate UBC

George Tomlinson, Georis

More than ever, people with disabilities must come together as a unified group in society. How we support and help each other through crisis and every day hurdles will strengthen us as a community and as individuals. Living independently is a choice and comes with additional challenges. Through unification people with disabilities make a difference; each voice is important.

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The goal of this meeting was for Peers to come together and share information and updates on current issues facing people with disabilities. The meeting was attended by approximately 77 people.

Special Announcement – Laura Mackenrot, Persons with Disability Advisory Committee

- The \$600.00 Pandemic Pay coming in the fall
- The Extension for the Disability Tax Credit is until December 31st, 2020
- Plan Institute is working in collaboration with other organizations and would like to inquire about having members sign up
 - Disability Alliance BC (DABC) assists people with their DTC application
 - Helpline: 1-844-311-7526
 - DABC has a new app which is additionally helpful
 - <https://disabilityalliancebc.org/dtc-app/>
- Building momentum for the Canadian Disability Benefit 4-part Learning Series Webinars
 - <https://planinstitute.ca/learning-series-canadian-disability-benefit.>
 - November 5th, 12th, 19th, and 26th
 - Each are 90 minute sessions about the National Disability Benefits that is being proposed

Questions and Answers

Q. Do people who already have the Disability Tax Credit need to register again?

A. No registration is needed if you already have the credit. The first payments will be coming around October 30th and will be deposited directly into your bank account if you have signed up for direct deposit, otherwise a cheque will come by mail.

Q. Is it correct, that if you are a PWD and you have a Disability Tax Credit you might get less than \$600 because the PWD have been given an extra \$300 for the last few months?

A. I have no knowledge about this matter at this point. The Pandemic pay is not supposed to affect other income sources that you may be getting. You can follow up on this but as far as we are concerned that information is incorrect. You would be able to get the \$600.00.

WE TALK TECH – Ean Price

<https://mailchi.mp/technologyforliving/introducing-we-talk-tech>

Wayne Pogue (Team Lead, Biomedical Engineering) and Ean Price (Innovation Strategist with TFL) have launched a new project to engage in dynamic back and forth discussions about the merits and downsides of different types of cutting-edge technology that may be of use to our peers.

Wayne and Ean, the “WE” in WE TALK TECH, will host short episodes every first Thursday of the month, starting November 5th, 2020.

You can expect their honest, expert opinions to be presented in their easy-going style. A Special Bonus for the members; you can contact TIL about any of the topics discussed at til@technologyforliving.org and speak with them about an installation possibility in your home.

They are also pleased to announce special guest appearances by Taylor Danielson.

YouTube Channel: <https://www.youtube.com/playlist?list=PLiTnJHTYWPbLZeHn30zyOGIQvS3hwkrAh>

First Episode: Introduction <https://www.youtube.com/watch?v=eREmb-fERGY&list=PLiTnJHTYWPbLZeHn30zyOGIQvS3hwkrAh&index=2>

Second Episode: Voice Assistants <https://www.youtube.com/watch?v=1Ta-0BLpdyY&list=PLiTnJHTYWPbLZeHn30zyOGIQvS3hwkrAh&index=1>

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Questions and Answers

Q. Are you going to connect this to the YouTube mainstream because I listen to tech information through my google home and I can give it commands to say "Give me the Tech News". It would be great if you mainstreamed it to give us access.

A. Yes, we are thrilled to connect to the mainstream

Participate in a Research Study - Elizabeth Straus UBC PhD Candidate

Elizabeth Straus extended an invitation for youth and young adults who use ventilators to participate in a Research Study, to help her and her team to learn about their daily lives.

The study provides an opportunity to share your stories, what is important to you and identify things that make things easier and/or harder for you; this is an opportunity for your voices to be heard.

The study also provides an opportunity to connect and talk multiple times over the course of a couple months at a time where it is easy to feel more isolated. Participants will receive an honorarium of \$80.00.

The collated overall findings of the study will be shared with health care providers and policy makers in British Columbia with the hope of influencing services and policy not only for those with ventilators, but also the study could more broadly effect policies for those with physical disabilities who don't use ventilators.

Conversations and interviews will occur primarily online or by phone during the pandemic. Any visits, if possible, would occur at home, in your community or any other location that you choose.

If chosen to be a participant, Elizabeth and her team will have conversations with you about yourselves, your everyday lives and what is important to you. You will also create a collection of photographs taken on your own or with the help of others that help tell about your daily lives and share stories about the photos in an interview.

Contact Elizabeth Strauss:

Telephone 604-788-8592 or email her at elizabeth.straus@alumni.ubc.ca

Study Recruitment Flyer:

<https://www.ifrcsociety.org/documents/pathways/HMVStudyRecruitmentFlyerBC.pdf>

Questions and Answers

Q. How many participants are you looking for?

A. Approximately 15 to 20 participants.

Q. Is there a deadline; what is your timeline?

A. We remain flexible. Due to the pandemic there is no deadline. I plan to work with people into the next year depending on what the individual needs and availabilities are. We recognize that things like hospitalization may occur and will accommodate participant's needs for extra time.

Q. Can we get the questions ahead of time to compose some responses beforehand?

A. Yes. Part of the process is to have phone conversations back and forth to see what would work best and we offer to forward the list of questions prior to the meeting to save time and energy.

Q. Will the participants have an opportunity to review the overall results?

A. The actual dissertation itself, in its entirety, is going to be made available and will be available in different venues. Once I start working through analysis, I will send it back to the participants before submitting it to make sure that I have interpreted information correctly.

Georis Update Presentation – George Tomlinson

<https://www.ifrcsociety.org/ppe>

Provincial Health Officer, Dr. Bonnie Henry, has stated we are now in the 2nd Wave and the rising numbers are of great concern.

The IFRC and George Tomlinson created the IFRC PPE Project in response to the need for appropriate PPE for CSIL and CLBC employers and their staff. The online store has been a success as we have been able to source many of the items people are looking for.

- **This initiative is a not-for-profit venture and is selling items at cost only**
- With the recent numbers, we are starting to see a spike of PPE requests. It is expected as people are getting worried and do not want to be caught without PPE.
- **We do not foresee a shortage of PPE. However, the price on some products is steadily increasing.**
- We are working to maintain stock of the most necessary items and we have obtained large quantities of the most critical items;
 - Medical Masks and Face Shields
 - Gloves
 - Unfortunately, prices on gloves are increasing
 - Some items like Lysol Wipes are available, but at an extremely high price
 - Limited number in stock; employers are encouraged to find alternate solutions. i.e. disinfectant and paper towels to save money
- Masks are of varying qualities and it depends on your work environment. Caregivers are often in close contact with the employer or you may be outside and socially distancing yourself
- For those who depend on caregivers for personal care they need masks like the ones that hospital nurses wear
- With the masks it is not about the price, but about the quality
 - The difference in price is significant. They make look the same, but some do not have the protection that the high-quality masks have for the personal protection needed.

- Low quality masks do not seal properly around the nose and mouth.

Paul Gauthier: Continue to follow the guidelines for protection because for many of us it is a matter of life and death.

- The latest release from Dr. Bonnie Henry noted that if you are a person with disability you can be exempt if you are unable to put on your masks
- Dr. Henry requests that the public abstain from having guests during this new wave
- The Association of CSIL Employers will be requesting an additional six month extension of the eligible CSIL expenditures such as the payment for family members policy.
 - The current exception is in place until December 31st.

Zoom Webinar

We have had many inquiries on how to stay safe and what is the appropriate PPE to use. Please refer to the descriptions and information on the website; <https://www.ifrcsociety.org/ppe>

- A Webinar series is being designed for CSIL and CLBC employers. The Webinar will help you build a COVID Safety Plan that will protect you and meet WorkSafe BC legislation. The Safety plan will also help your caregivers understand what is expected from them.
 - The Safety Plan will meet WorkSafe BC and the BC Centre for Disease Control requirements
- Preregistration will be necessary so participants can be sent a packet prior to the Webinar.
 - The packet will include a checklist of questions to be answered prior to the Webinar
 - The questions will be the foundation of your Safety Plan
- Contact
 - **Emails will be sent out with dates for registration once they have been scheduled**
 - **Or you can email George at george@ifrcsociety.org to learn the dates of the webinars and how to register.**

Georis online: <https://www.ifrcsociety.org/ppe>

Questions and Answers

Q. Do you have any gloves in stock that are in size large?

A. Yes, up to extra-large sizes available. Gloves have been an issue and because the price keeps increasing we are purchasing more of the medium since they are most commonly purchased. However, we do have larger sizes.

Q. Who have you partnered with for your deliveries, is it delivered to our homes?

A. Volunteers deliver it in person throughout the Lower Mainland, and for out of town we use Canada Post and it is 3 or 4 days delivery time.

Q. Does CSIL cover masks for caregivers in our homes?

A. PPE, or Universal protection equipment, is an eligible expense for CSIL Employers. Currently there is an exception to the \$40 a month cap due to COVID-19 until December 31st, 2020

Q. Due to the fact that COVID numbers are going up, would immediate family members likely to be approved for being hired for care?

A. The current exceptions to policy allows CSIL Employers to hire immediate family members. This is until December 31st, 2020, but the ACE Executive will be requesting an extension due to the second wave of COVID we are now experiencing.

Q. How do we pay family members?

A. Family members must be put on the CSIL Payroll and paid as a regular employee.

Q. Are disinfectant wipes counted as PPE?

A. Disinfectant wipes are not on the approved list, but hand sanitizer is.

Discussion

Participant: For disinfectant wipes, I use unscented baby wipes and I add some liquid disinfectant cleaner to the container. The wipes stay moist in the container.

Peers stated that with the increased numbers of cases, they fear going out in public. One peer wishes to get a flu shot, but is fearful of going into the public to obtain one.

BC Ministry of Health Policy: Mask Use in Health Care Facilities During the COVID-19 Pandemic- November 4, 2020

Stephen Brown, Deputy Minister, Ministry of Health, released this new policy on November 4th, 2020

Excerpts from the policy are as follows:

Policy Objective: This Policy protects patients, clients, clinicians, health care workers, non-clinical staff and the public by outlining provincial expectations for the use of face masks in all health care facilities, programs and services, including community physician offices and outpatient clinics during COVID-19 pandemic.

Definitions:

- **Medical mask:** A medical grade face mask that meets ASTM International and ISO (or equivalent) performance requirements for bacterial filtration efficiency, particulate filtration efficiency, fluid resistance, pressure differential, flame spread, skin sensitivity and cytotoxic testing
- **Must:** A mandatory requirement based on the BC Ministry of Health directive

Guiding Considerations: Masking guidance should be based on current evidence about the known mechanisms of the COVID-19 transmission. Specifically, COVID-19 is spread by liquid droplets that come from the mouth and nose when a person coughs, sneezes, and sometimes, when a person talks.

Other Health Care Facilities and Settings where Health Care is Provided

- **Health care workers and non-clinical staff:**
 - All persons working in a clinical unit/setting/patient care area **must** wear a medical mask, including in common areas and break rooms unless eating and/or drinking.
 - All persons working in non-clinical settings **must** follow guidance for mask use in accordance with their workplace COVID-19 Safety Plan(s) required by WorkSafe BC.

The full policy is located here: http://www.bccdc.ca/Health-Professionals-Site/Documents/Mask_Use_Health_Care_Facilities.pdf

BC Centre for Disease Control Guidance documents can be found here: <http://www.bccdc.ca/health-professionals/clinical-resources/covid-19-care/new-today>

Temporary Pandemic Pay Update – Employer Costs

A major concern for the Temporary Pandemic Pay has been the Employers cost related to providing the \$4.00 pay. There are many CSIL Employers who are in a deficit or they do not have adequate surplus in which to cover the employer costs.

- The government has confirmed they will provide Employers with 10.1% of eligible claim amount to cover employer costs
- Verified claims will be covered for the \$4 per hour wage top up, plus 10.1% for employer costs

Questions and Answers

Q. You were going to advocate for payment to family. Did that go through for paying for the masks also?
 A. Yes, ACE did advocate for this and the Ministry responded positively. The exceptions from Ministry of Health are valid until December 31st, 2020. The ACE Executive will be requesting an extension given the current COVID-19 situation.

- The updated policy for CSIL exception of July 2nd, 2020 extending to December 31st, 2020;
 - <https://www.ifrcsociety.org/documents/pathways/20200702MinistryofHealthExtensionJuly2020.pdf>
- Details:
 1. In the current CSIL Expense Guidelines, sick pay is listed as an optional expense at 2%-3% per year, to a maximum of five days per year. This pay is required to be expensed from the overall funding that is provided to CSIL employers.

Exception to Policy: HAs to allow a time-limited exception and permit CSIL employers to allocate surplus funding towards two weeks of pay for CSIL employees required to self quarantine. If a CSIL employer lacks adequate surplus to cover the payroll burden, the HAs will provide temporary financial relief on a case by case basis, with adequate justification and supporting documentation from CSIL employers.

2. Current HCC policy: CSIL employers are responsible for creating a respite plan and a backup service plan to ensure care needs are met on a continuous basis and HAs may authorize home support services from an agency in exceptional circumstances, such as short-term acute illness, to augment CSIL funding.

Exception to Policy: The Ministry allows HAs to temporarily suspend the requirement to obtain prior approval to use agencies for emergency staffing.

3. Current Home and Community Care (HCC) policy states that “an immediate family member cannot be paid to provide care for a client unless an exception is approved by the HA.”

Exception to Policy: The Ministry allows CSIL Employers to temporarily pay immediate family members (including an immediate family member who has been appointed power of attorney or representative of the CSIL employer) to provide care, without the requirement to obtain prior approval, if their supply of regular staff and back up care plan staff has been impacted.

CSIL employers must continue to inform their case managers of any changes in their care, including the hiring of immediate family members

4. CSIL Expense Guidelines allow employees to expense \$20-\$40 per month for supplies required for universal precautions and safety such as disposable gloves, masks, and hand sanitizer.

Exception: CSIL clients will temporarily be permitted to expense greater than \$40 per month towards universal precautions and safety. If needed, HAs will provide additional funding for gloves, masks and hand sanitizer on a case by case basis, to help preserve the health care supply chain of Personal Protective Equipment (PPE), with adequate justification provided by CSIL employers.

CERB Support

The Canada Emergency Response Benefit (CERB) gives financial support to employed and self-employed Canadians who are directly affected by COVID-19.

If you are eligible, you can receive \$2,000 for a 4-week period (the same as \$500 a week).

Link: <https://www.canada.ca/en/services/benefits/ei/cerb-application.html>

How to prepare to request more Home Support Hours

The maximum number of hours an individual receives can vary depending on your individual need and based on your physical requirements. Assessments performed by the Health Authorities can also vary differently. We will share information about support and policies that are in effect. Peers report that some are not getting enough hours, have been reduced hours or just looking to possibly get more hours.

- The Time Task Analysis is used for assessment and are supposed to follow the Ministry of Health guidelines with CSIL approved times that the Ministry of Health has put forth.
- The Vancouver Coastal Health Time Task Analysis provides guidelines for tasks like bathing, brushing teeth, personal care routines etc.
 - You can find the PDF document link here: <https://www.ifrcsociety.org/documents/pathways/20201027VCHATimeTaskAnalysis-updatedversionFeb2014.pdf>
 - For those who would like the Excel working sheet, please email your request to pathways@ifrcsociety.org
- Fraser Health CSIL Approved Standard Time and Tasks
 - Pdf: <https://www.ifrcsociety.org/documents/pathways/FHA%20CSIL%20Approved%20Standard%20Time%20and%20Tasks.pdf>
- Although the Analysis has a list of times, you can make a case for an exemption if your particular disability takes longer
 - If you can make the case for the exemption, the case manager must review the possibility of giving more hours for those tasks
 - The case manager is not the end decision maker, they are the ones that gather information and present it to their managers

- The more information that you can provide your case manager the stronger your position is that the case manager can present on your behalf
- It is better for you to connect your request to a medical need with notes or letters from your doctors.
 - If you can connect your need for daily showers/baths to something like skin integrity issues, incontinence, or an existing skin condition, that will strengthen your request
 - If you have difficulty swallowing and it takes longer for you to eat so you don't choke, connect that detail to your request for more meal time assistance
- There are many kinds of case managers; some are experienced and have a lot of understanding, but there are those who are new and may lack the insight necessary that comes with experience
- Preparing a Supported Lifestyle Plan (SLP - similar to the time task analysis) ahead of your assessment helps you to communicate effectively with your case manager
 - In order to convey what your worst day is for you (and we know how often those happen), build your SLP around that
 - Outline the routines and activities on how a caregiver will do them, not a family member
 - SLPs prevent you from forgetting the little things that add minutes up in a day
- Supported Lifestyle Plan sample document link here:
<https://www.ifrcsociety.org/documents/pathways/202011SLPSAMPLE.pdf>
- **Peer Comment:** They only want to give you 1 shower a week and if you miss a shower, you're out of luck and stuck without a shower (agency)
- **Peer Comment:** It is criminal what is happening in the long term care senior residences and even in the community
- **Peer Comment – Andrew Pejkovic:** I have been dealing with home care for a long time and to help me deal with a lot of the problems and issues surround homecare I started a website called The Home Care Network.
 - I am an advocate and created this website which has a lot of information and resources to help you navigate the system and help provide you with extra support so that you can work with your case manager and to get more hours for home support. You must connect it with medical notes.
 - Link: <https://www.thehomecarenetwork.ca/>
 - The site is run by clients, caregivers and volunteers and is a valuable resource for navigating the BC Health Authority websites and directives.

Question and Answer

Q. Has anyone ever used a lawyer to get more hours?

Peer Response: Yes, I have.

Q. Has ACE ever asked the Ministry for the studies, or other means, that made them arrive at these figures in their time task analysis?

A. The InterRAI Clinical Standards and “Best Practice” Guidelines. This is a formulation and calculation that seems to have been developed for seniors and not for persons with disabilities and this is apparent when you examine the type of questions that are being asked

- An InterRAI Clinical Standards and “Best Practice” Guidelines needs to be developed to specifically target the disability community with appropriate questions
- People with disabilities need to be heard; the public needs to hear about our issues
- People on CLBC get support for community inclusion dollars so that they can go out into the community and fully participate, and we need this provision for people with physical disabilities as well
- More on the InterRai Clinical Standards and “Best Practice” Guidelines: https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/accountability/pdf/final_rai-hc_guidelines_-_2016.pdf
- The issue is people not getting enough hours. The appropriate number of hours should be provided; many can’t be left alone.
 - ACE has been doing a lot of lobbying around changes to the CSIL program
 - We got the hourly rate increased over the years
 - The issue now is not about the hourly rate, the issue is people not getting enough hours in the first place
 - If people got the right number of hours, we would be able to pay a competitive hourly rate
- ACE needs to start focusing on having the policies updated so they are related to the tasks that can be done so that the appropriate number of hours can be provided.
 - There are people who are on ventilators and need a staff presence for long periods of time
 - There are not always physical activities being done but they cannot be left alone, and employees are expected to be paid if they are going to be there for any period of time
 - Employers who are forced to pay a flat rate for 24-hour shifts would like to pay more because staff deserve a lot more; they are away from their family and friend so they should be paid for their time
- The idea of changing policies takes times and there has been several discussions about Pathways breaking into smaller groups to work on these advocacy pieces.
 - Bringing back the information to Pathways keeps community engaged and allows for broader input on issues of importance and that may benefit from group consensus

Developing Your Supported Lifestyle Plan (SLP)

- An SLP is a comprehensive picture of what your needs are and documents all the tasks that you need assistance with. This will help you form a strong basis for having a conversation with your case manager.
 - Their job is to come in gather the information and make that sure that you are safe
 - Have a list of what your medical condition is like and what the issues are which you are dealing with from a health perspective
 - You need to connect these to why you need the personal care done
- Using a bullet form for your document and putting routine minutes next to them, makes it easier for the case manager to go through it quickly with you
 - **By placing your current medical details at the top of the SLP, the case manager is able to start off your assessment knowing your current status**

- Include medical updates and current medical information
 - Document all the mobility assistant devices you use such as a ceiling track lift, a commode chair, electric chair, and electric bed
 - List the medication(s) you are taking and have your medicine bottles out to provide them rather than have the case manager go and find them
 - Add another column to list the medication DIM number because they will also require this information
 - Include current treatment and/or therapies you are having done
- After your heading information, start documenting your 24-hour care with concise information on current needs
 - Break routines down step by step
 - Split your day into Morning, Afternoon, Evening and Overnight
 - If you have complicated routines, a step by step outline will help validate extra time you are needing
 - If your routine takes your caregiver extra time to prepare for, include that
- If the Health Authority knows you can shower yourself, but it takes a long time and is unsafe, explain this so they have a thorough understanding of why you need the support
- List your medical reasons for having the routines done daily/frequently
- Include Range of Motion (ROM) exercise in your SLP
 - Some Health Authorities will allow for the time for that and others will not. It is recommended to list it. If it is a physical activity that needs to be done to benefit your health, then it should go in.
- When it comes to meal preparation, and even though they won't allow for the time of 30 minutes to prepare your dinner, because many of us have heard from case managers that they are only allowed to warm up our meals.
 - I.e., 10 minutes to warm up foods. From an advocacies perspective this is outrageous as well. Unfortunately, the system that we are in, warming up of the frozen food is acceptable, but unhealthy
 - If you require assistance to eat, have your food prepared in a particular way to prevent choking or your disability prevents you from swallowing quickly, detail the information with the support of a doctor's letter
 - I.e., if you are prone to UTIs then you also need to manage your diet and need to have an appropriate amount of fluid intake
- Reducing bacteria with home cleanliness, good hygiene, toileting care and bowel issues are important to outline in detail
- Especially now with COVID-19, Employers are required to have Safety Plans that include regular disinfection of surfaces in the home to adhere to the BC Centre for Disease Control recommendations
- If you are having washroom accidents, you must talk to your case manager about the situation so they understand that more time is require for either the clean up or to go to the washroom more often
- Include how many supported visits to the doctor/dentist etc, you take in a year and place them in a separate category called Non-Daily tasks
 - To get the numbers to add to your daily account of minutes, i.e.

<ul style="list-style-type: none"> • 90 Mins 4x Year <ul style="list-style-type: none"> • /360 • 1 Min Day 	Specialist Medical/Family Doctor appointment <ul style="list-style-type: none"> • Accompanied by Caregiver • Require staff to assist with getting on/off examination bed • Assist with clothing removal and redressing
90 Mins 2x Month /30 6 Mins Day	Regular Blood Work for UTI Prevention <ul style="list-style-type: none"> • Accompanied by Caregiver • Assist with clothing removal and redressing • Assistance with body placement for testing

- **Accompanying Documents**
 - Letter from Dr(s) to support your request
 - Material to demonstrate unique care needs
 - i.e. Occupational Therapist report/letter
 - Physiotherapist plan/letter

Supported Lifestyle Plan Sample found here:

<https://www.ifrcsociety.org/documents/pathways/202011SLPSAMPLE.pdf>

Maximum Monthly Hours

The Ministry of Health CSIL Categories of Need Guidelines demonstrates that people can get more than 4 hours a day.

- There are determinants such as the interventions at night
- The more interventions you have at night justifies the need for more support hours
- There are not many people out there who receive 420 hours per month
- There are those who have gone to their MLA
- You must be prepared to advocate for yourselves and developing your Supported Lifestyle Plan helps you communicate all your needs without missing important components
- This will help you form a strong case for your case manager when presenting your case for more hours
- There are 4 levels of needs;
 - Level 1 and Level 2 are Daytime Care Needs
 - Level 3 and Level 4 are Overnight Care Needs
- **Maximum Hours**
 - Level 1: 0-120
 - Level 2: 0-240
 - Level 3: 0-300
 - Maximum of 300 hours based on max. 240 hrs daytime needs + max. **60 hrs overnight needs (60 = 2 hrs x 30 days)**
 - Level 4: 0-420
 - Maximum of 420 hours based on max. 240 hrs daytime needs + max. **180 hrs overnight needs (180 = 6 hrs x 30 days)**
- Ministry of Health CSIL Categories of Need Guidelines 2011 found here: <https://www.health.gov.bc.ca/library/publications/year/2011/CSIL-categories-of-need-guidelines.pdf>

- Located also:
<https://www.ifrcsociety.org/documents/pathways/20201027UploadCSILcategoriesofneedguidelines.pdf>

Preparing a letter to the Health Authority When Requesting More Hours

- Write a courteous letter to the Case Manager
- Be clear in how you write your letter
- Avoid long sentences and paragraphs
 - The more you write, the less will be read because people skim when in a hurry
- State very clearly, the number of extra daily hours you are requesting
 - Outline how the current situation is impacting your health
 - Explain why your family cannot provide you with care
 - Outline need and how additional hours will support/improve your health
 - Be clear on how you plan to use the new hours
- If you are in a serious situation, don't hesitate to tell them that you're afraid of what will happen
 - Be clear on how critical the situation is
 - Don't be afraid to expose how vulnerable you feel

Peer Comment: I brought in a support worker to my appointment and the case manager was relieved that they did not have to be the ones to help me with the routines. The SLP is a great tool to help you remember and if you haven't had time to prepare.

Preparing for Your Meeting with the Case Manager

- When preparing for a meeting with your case manager you will be able use your Supported Lifestyle Plan to help you remember all your tasks that you need to have done in a 24hr day
- Arrange a date for a home or remote visit, such as Zoom
 - Please note that some Health Authorities will perform an assessment in your home only
- The case manager must ask you questions
 - They will ask how many times you go to the bathroom every day and if you haven't had time to think about it, off the top of your head your response may be too low.
 - However, when you do your Supported Lifestyle Plan you will see that you may actually go 6 or 7 times per day so you can use the SLP as your response notes
 - There may also be the case that family members are doing things for your physically that you don't even think about.
 - Those things should be considered in your support plan as being done by caregivers
- Arrange to have a trusted person attend the meeting with you; you'll find it a tremendous help
 - You can call on a friend to be there
 - If you have a Representative, you may want to ask them to join you
 - They can help with asking questions and/or remind you of things you want to discuss
 - They can be witness to conversations
 - Can help you write down key points said in the meeting you wish to remember
 - Help you document points you and your case manager have agreed upon
 - Physical Support
 - Having someone on hand for physical support will make the assessment go smoother for both you and the case manager

- Someone who is experienced in physically supporting your routines
- Have a printed copy of your SLP on hand for you to refer to, and to provide to the case manager if you choose to
 - Use the SLP to help you communicate your needs clearly
 - The SLP helps you stay on track and you don't forget things
- Be mindful of what you say, even in passing
 - **Talk about what you can't do, not what you can as the case manager needs to know your needs very clearly**
- Case managers do not make the final decision on hours
 - They take their recommendations to the Managers in their respective Health Authority
 - It is the Managers who make the decisions and inform the case manager of their decisions, or discuss any questions or concerns they may want clarified
 - Depending on the hours you are requesting, the Health Authority may often wish to perform an assessment using a stopwatch

Peer Comment: The use of Stop Watching Process becomes redundant if we have a developed Lifestyle Plan because they should be able to take our word for it. It brings upon the feeling of being on trial or something offensive. This shouldn't happen, but it is something we are forced to endure.

How to Appeal Health Authority Decisions

- If the Health Authority denies your request for more hours, or has not given you enough hours, request a letter that informs you of their decision and outlines their reasons for not providing you with what you requested
- Some CSIL Employers report that their case managers have told them they can't give out letters
 - You need to be persistent; the decision is about your life, and you must have a letter/email
 - You have the right to know why you are being denied hours and this letter is vital
 - Not all case managers like to correspond via email but if you could get them going on this, it is to your benefit.
 - Gently push back if necessary, but remain polite
 - Tell the Case manager that you will be appealing the hours and ask them how to proceed with an appeal

Peer Comment: My case manager refuses to communicate by email

Peer Response: I insist on email only in communications so I can use it as evidence later on

Peer Comment: I have asked for more hours 6 weeks ago and they said there is no case worker in my area and the rest are on call; they will get to me, when they get to me

Appeal Letter

- An appeal letter is an enhanced, stronger version of your original request for more hours which you originally gave your case manager
- You do have the right to appeal the decision and there are many levels of appeal. Fraser Health has a mediation process where you can request a mediation and that is when the Director of the CSIL program will meet with you and your advocate
- IFRC has done a lot of facilitation meetings and it helps give clarity. Fraser Health has had great success with these facilitation meetings

- The Director get to hear firsthand from the member and gains great clarity when receiving new information that may not have been initially translated over and with that, could determine that a wrong decision was made
- Fraser Health has done a great job in adding this component

Patient Care Quality Office (PCQO)

- If in the end you are not satisfied with the result (hours) have the right to go to the Patient Care Quality office.
 - All Health Authorities have a PCQO
 - When you send a letter or email be clear and provide as much information as you can
 - Write what resolution you are seeking
 - It starts off with an internal process, they are reviewing the information you provide on top of their own documents to determine if the right decision has been made
 - PCQO will determine if it was a fair process or not, and either make recommendations for a resolution or present a final decision
- Patient Care Quality Offices
 - **Fraser Health**
 - Patient Care Quality Office
Fraser Health
11762 Laity St, 4th floor
Maple Ridge, BC V2X 5A3
Tel: 1-877-880-8823
Fax: 604-463-1888
E-mail: pcqoffice@fraserhealth.ca (or via this form)
 - **Interior Health**
 - 505 Doyle Avenue
Kelowna, BC
V1Y 0C5
Toll Free Number: 1-877-IHA-2001 (1-877-442-2001)
Fax: 250-870-4670
 - Office hours: 8:30am - 4:30pm PST; Monday-Friday, excluding statutory holiday
 - **Vancouver Island Health Authority**
 - Patient Care Quality Office
Royal Jubilee Hospital
Memorial Pavilion
Watson Wing, Rm 315
1952 Bay Street
Victoria, B.C.
V8R 1J8
 - **Hours:**
Monday - Friday 8:30 a.m. - 4:30 p.m.

(closed on weekends and stat holidays)

In-person meetings are available 8:30 a.m. - 3:30 p.m. during normal business hours.

- 250-370-8323
Toll-free: 1-877-977-5797
Fax: 250-370-8137
- patientcarequalityoffice@viha.ca
- **Vancouver Coastal Health**
 - Phone
1 (877) 993-9199 (choose the option to direct your call to the correct site)
Fax (604) 875-5545
 - Mail
855 West 12th Avenue
LBP-380
Vancouver, BC V5Z 1M9
 - Email: pcqo@vch.ca
 - In person
Visit one of the locations below. Office hours are Monday to Friday, 8:30 a.m. - 3:30 p.m. Closed on statutory holidays.
- **Northern Health**
 - 6th floor 299 Victoria Street
Prince George, BC V2L 5B8
Toll-free: [1-877-677-7715](tel:1-877-677-7715)
Fax: [250-565-2640](tel:250-565-2640)
Email: patientcarequalityoffice@northernhealth.ca
 - The Patient Care Quality Office is open Monday to Friday (except statutory holidays) from 8:30 a.m. – 4:30 p.m.

If you are still not satisfied

There are further options available to you if your request is denied by the Patient Care Quality Office, which some CSIL Employers find successful.

- You have the right to move to the next level of appeal which is to directly contact;
 - **Ministry of Patient Care Quality Review Board**
PO Box 9643
Victoria, BC V8W 9P1
Phone: [1-866-952-2448](tel:1-866-952-2448)
Fax: [250-952-2428](tel:250-952-2428)
Email: contact@patientcarequalityreviewboard.ca
Website: patientcarequalityreviewboard.ca

Additional Advocacy Options

- Send a letter to your MLA outlining your needs and the difficulties you are experiencing with the Health Authority.
 - Send an equally informative and passionate letter to your MLA
 - Keep in touch with your MLA

- Keep them up to date and develop a relationship with them
- They are very much the people who understand people issues
- Request their intervention when needed
- **MLA**
 - Please note that the links may not be up to date due to the election
 - Find MLA by Community: <https://www.leg.bc.ca/Pages/BCLASS-Search-Community.aspx?PlaceFirstLetter=A&>
 - Find MLA by Constituency: <https://www.leg.bc.ca/Pages/BCLASS-Search-Constituency.aspx>
 - Find by Postal Code: 1-800-661-8683
 - There is usually a map that shows the MLAs for regions and neighbourhoods, but it is currently offline due to the election
- Failing getting the response you need, you can write directly to Adrian Dix, Minister of Health
- Describe, with courtesy, the problems you have encountered with the Health Authority
 - Examples:
 - The Health Authority did not understand your medical needs
 - The Healthy Authority did not take certain aspects of your care into account
 - Repeat all your care needs and information
 - Request their assistance
- **Ministry of Health Directory**
 - URL: <https://dir.gov.bc.ca/gtds.cgi?show=Branch&organizationCode=HLTH&organizationalUnitCode=MH>
 - Adrian Dix, Minister of Health
PO Box 9050
Stn Prov Govt
Victoria, BC V8W 9E2
Email: HLTH.Minister@gov.bc.ca
Telephone: 250-953-3547

Question and Answer

Q. Should I ask for an appeal or just increased hours? I was not given what I need last December but have just been trying to make it work!

A. You have 40 days to make an appeal. As it's almost a year later, you can start the process by requesting more hours

Peer Comment: I am here representing my wife and we are with Vancouver Coastal Health and our experience is that we never see the same case manager twice; it is a revolving door. They are always very inexperienced and the consequences of that is that you tell them what you want and they go back to their manager who says no and ultimately the answer is you get no more hours.

I am about to have a hip replacement which makes me incapable of doing the bit that I do, and we raised that as an issue, but they still say no more hours, you are on your own.

A. Have you gone further up the chain of command?

Peer's response:

No, we have stayed with the case manager, she tried to help but she came back with management's decision that we weren't entitled to more. I didn't even know which direction to go further up the chain. My wife is on CSIL and we usually must top up the amount of about \$800. 10-15 hours more per week needed because of the knee surgery that I am scheduled to have and through the healing process that could last anywhere from 4 -12 months, the duration of the healing process is unknown.

A. I understand your situation is time sensitive depending when you get the call to go in for surgery. Some people are able to get more hours when it becomes an emergency and in this case you are trying to be proactive, and in a pro-active way you could start by creating a Supported Lifestyle Plan. It is time to call the Patient Care Office and talk about the preventative measures that you are trying to make knowing that you are going into the hospital.

You have strong arguments to get the process started. When it comes to the Patient Care Quality Office, a simple phone call can be made, and it gets the process started. Some people choose to write a letter so that they can express all their thoughts in details. Whatever works best for you as a family.

Either way, make the state "We are not being unreasonable; we know the support needs are going to be much higher when I am hospitalized and during my recovery months and my will will require temporary additional hours." Get a doctor's opinion on how long they would expect the healing process to take and put that forward through the Patient Care Quality Office.

However, you will also need to express very clearly that you are already not getting enough hours and will need a fair assessment on those hours of need.

The Peer will be supported offline.

Peer Comment: I get quite a few hours; I got a meeting with a new case manager because as of next week I have two days that I have nobody to cover me because I have placed an ad, and nobody is answering me. It has been like that for about 2 years now. I would be lucky to get 2 or 3 people answer the ad and maybe 1 or 2 people would show up for an interview. This was the first time since I was involved with the pilot project for CSIL that I have not had even one response. I reside in Saanich and I started a Facebook page about Share Our Support Workers.

A. That would be something great for you to share with us. The Association of CSIL Employers (CSIL ACE) has a Facebook page that you may want to tap into:

<https://www.facebook.com/groups/CSIL.ACE>

Peer Contributions & Feedback

- "It was an Information Packed Pathways meeting!"

Peer Contribution to Making an Appeal with the Health Authority-Rowland Gould

- Things You Should Know about Registering an Appeal with CSIL
 - <https://www.ifrcsociety.org/documents/pathways/ThingstoknowwhenregisteringanAppealwithCSIL.pdf>
- VCHA Formal Review Process
 - <https://www.ifrcsociety.org/documents/pathways/VCHVCAOAFORMALREVIEWPROCESSREVISED2011.PDF>

- Some great resources for people with disabilities and seniors during COVID times and meal resources are included. You can find one of the peer's document here on the IFRC site: <https://www.ifrcsociety.org/documents/pathways/COVID-19-PREPARE-AND-PREVENTION-FOR-PERSONS-WITH-DISABILITIES-AND-SENIORS.pdf>
- Vivian Garcia is on a Covid Task force for New Westminister. She is working on grants for Housing and Wi-Fi, which not enough is about it is discussed about, but free Wi-Fi is important. They are working on foods and PPE and everything else that can and should be done.
 - What inspired her about Pathways is that sometimes one needs to be nudged about things like the cost of gloves and links to websites for resources.
 - The city of New Westminister has a Covid 19 website where you can find information about funding, food etc.
- Vivian Garcia has graciously provided additional resources:
 - **Mentor Works; Accessible Technology Program (ATM)**
The Accessible Technology Program is a Canadian government grant designed to support the development and testing of assistive technologies. It seeks to improve digital/knowledge economy participation among persons with disabilities.
<https://www.mentorworks.ca/what-we-offer/government-funding/research-development/accessible-technology-program/>
 - **The Best Way to Diversify your Income: Build a Business.** Google Podcast on Canadian Money The Best Way to Diversify Your Income: Build a Business and they mentioned how RBC has a whole learning hub for small businesses. This would fit with videos on technology.
<https://podcasts.google.com/feed/aHR0cHM6Ly9idWlsZHdIYWx0aGNhbmFkYS5saWJzeW4uY29tL3Jzcw/episode/NDdhNTlkNTYtODdkYy00NjliLWI1ZjQyYTNkZDk2YzA5NDg0?ep=14&fbclid=IwAR1Qvwdc5Vea8NJIPOW9dzShL9k6STQemD32PUyH9HPv0GaTddveuWH0rp0>
 - **Telus; Connecting Canadians in need with Internet for Good®**
 Having access to reliable internet is essential in today's interconnected world, but for low-income families and people with disabilities, it can still be a struggle. Internet for Good® is an innovative program offered in BC and Alberta that provides eligible Canadians with the tools and connectivity they need to succeed.
 - <https://www.telus.com/en/about/company-overview/community-investment/how-we-give/cause-campaigns/internet-for-good>

Closing Remarks

- A big thank you to Ean Price from Technology For Living, Elizabeth Strauss, and George Tomlinson for participating in the meeting. Their presentations were interesting and really enjoyable for everyone!
- The Pathways Team would also like to thank all the peers for contributing information, feedback and their valuable experience and networking solutions to this meeting. Opportunities come from collaboration and teamwork and we're looking forward to following up with individuals.

- If any other peers are involved in outreach projects and/or activities for individuals with disabilities and would like to announce them to the group, or do a presentation, please contact Hilary Currie at hilary@ifrcsociety.org

Pathways To Independence Meeting November Topics

- Topics to be confirmed
- Peers are reminded that if they have a topic idea for a future meeting, to please send an email to pathways@ifrcsociety.org

Pathways To Independence Meetings Dates

Upcoming Meeting Dates:

- Thursday, November 26th, 2020 1:30pm to 3:30pm
- Wednesday, January 27th, 2021 1:30pm to 3:30pm

Pathways To Independence Peer Group Meeting Notes and pertinent documents are uploaded to <https://www.ifrcsociety.org/pathways>

This was a virtual Pathways To Independence Meeting via Zoom technology. In partnership with Technology for Living, whose Technical Team, headed by Ean Price, successfully ensured that peers could connect to the meeting from across the province.

THANK YOU EVERYONE, FOR YOUR ATTENDANCE AND CONTRIBUTION TO THE MEETING!