

turning point

a guide to community living for people
with a high level of physical disability



BC Association for
Individualized Technology and
Supports for People with Disabilities

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Coordinator | Kirsty Dickinson

Writer and Designer | Ann Vrlak

BC Association for Individualized Technology and Supports for People with Disabilities (BCITS)

Home of Provincial Respiratory Outreach Program (PROP) and Technology for Independent Living Program (TIL)

103-366 East Kent Avenue South, Vancouver, BC V5X 4N6

PROP 1-866-326-1245 | TIL 604-326-0175

fax 604-326-0176 | info@bcits.org | www.bcits.org

BCITS is funded by the Ministry of Health Services.



BC Association for Individualized Technology and Supports for People with Disabilities

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about this guide

This Guide is for people with a high level of physical disability who are at a turning point in their lives and want to live independently in the community.

“Independent living” can mean different things to different people. For the purposes of this Guide, we’re referring to people with a range of disabilities who want more freedom and autonomy in their living environment—or want to maintain the autonomy they have. For example, you may be:

- someone with muscular dystrophy or cerebral palsy, or someone recovering from a spinal cord injury who is ready to move from a rehabilitation facility into your own apartment;
- a person who has received a tracheostomy and now uses a ventilator most or all of the time, but you want to continue living in a shared-care residence; or
- a young person, nearing adulthood, who will soon be ineligible for the At Home Care program and would like information on how to continue living in the community.

We prepared this Guide for you to pick up when you’re ready to consider what’s next.

For people who are adjusting to life with a ventilator or a physical disability, or progressive illnesses that have radically changed their lives, there is a lot to digest and think about. Emotional turmoil can make decision-making and looking to the future seem difficult.

We prepared this Guide for you to pick up when you’re ready to consider what’s next. When that time comes, we hope this Guide will be a “friend” to help you make informed decisions and find helpful supports.

There are many pieces to the puzzle of a successful transition into an independent living environment. In this Guide, we focus on the pieces we think are most crucial, and provide information on where and how to find out more.

Who We Are

We are the BC Association for Individualized Technology and Supports for People with Disabilities (BCITS). We’re the home of the Provincial Respiratory Outreach Program (PROP) and Technology for Independent Living (TIL).

Our mission is to provide services and supports to help people who have severe physical disabilities to live safely and well in the community. You will learn much

more about us throughout this Guide. For now, here's an overview of what we provide for our clients:

- assistance and resources to help with the transition from a care facility to community living, or from one home to another
- Peer support from people living with high levels of disability and who have made successful transitions to living independently
- ventilators, supplies and support services for people who need assisted ventilation
- technology to help people with a high level of disability control various electronic devices in their home
- ongoing services, from Respiratory Therapists and Biomedical Engineering Technologists, once you are in your own home.

Guide Overview

Here's a look ahead at what you'll find in this Guide.

- ✓ **Confirmation that you're not alone.** There are people, especially those in our Peer Group, who have "been there" and will offer as much support, information or advice as they can.
- ✓ **Information from the direct experiences of our Peers.** In writing this Guide, we relied on the experiences of our Peer Group. We asked: "What do you wish you had known when you were making the transition into the community?" So, we hope the information in these pages will be very relevant and practical.
- ✓ **Ways for you to become as strong and resourceful as you can be.** Our Peers emphasized the importance of becoming both an expert on your own health and a strong advocate for yourself. As a result, there is a theme of personal development and empowerment throughout this Guide. Why? Because many of the roads to independence are not yet as "paved" as we'd like them to be. You will need to have a strong vision of what you want and to communicate it well.
- ✓ **The most important keys to living independently.** We've divided this Guide into the major parts of the transition puzzle, such as support from friends and family, housing and home support, training and more. We look at the key areas and point you toward where to look for more information.
- ✓ **True stories.** We look at two people's journeys to living in the community, and the skills and support they needed along the way.

It All Starts With You

It's true there are many aspects of living with a disability or moving into the community that will not be within your control. However, building your inner resources and strengths will increase your ability to influence and adapt to circumstances.

Here are some first thoughts from our Peers:

- Give yourself time to learn, change and grow in your new condition and your new life.
- Know when you need support and ask for it.
- Read, talk to people and explore—staying connected with people is a key to personal strength and perspective.
- You may need to learn new behaviours. For example, you might be the kind of person who doesn't like to ask for help. But, as one of our Peers said, "It may sound strange, but learning to ask for help is a key piece on the road to independence."
- Be an active player in your own life. Being passive about life changes or decisions, may in some ways be easier. But, you will probably not end up where you truly want to be.

By working with your inner attitudes and abilities, you will be in a much stronger frame of mind to manage your move into the community and create the kind of life you want.



We all moved to the community in our own way and at our own pace. It's always individual. There's no right or wrong way, just what works for you.

To Boldly Go...

This Guide was made possible by the work of some trailblazers—people with disabilities who nobody believed could live outside of institutional settings.

These people—like Rob Dunfield, Jeanette Andersen, Mary Williams, Cody Tresierra and Walt Lawrence—had a vision. They saw themselves living lives that were essentially the same as people living without a disability. They were the driving force behind some of the first shared-care residences in BC, like Creekview Housing Cooperative and Noble House Cooperative.

Their lives showed the impossible was in fact possible and more people with disabilities "think big" because of their example.

personal development

Living with a disability means you will have some degree of contact with social and health services: health care professionals, case managers, the administration of the facility you are living in, housing organizations, government benefits workers, and others. You'll also have your personal relationships with family and friends. All of these people will have some information or ideas that will help you prepare and make decisions.

And, most of these people will have opinions—sometimes strong ones—on what is best for you. So, you will need two things:

1. a personal vision of how you want to live and a plan to create this reality
2. the assertiveness and self-confidence to follow the steps to get you there.

Your Vision

We provide resources in this Guide to help you develop your vision, to encourage you to think big. For example, you can talk with one of our Peers about living in the community and what it means to you. Or, you can use the Personal Strategy Tool in the appendices. This tool starts with your wishes and goals, and provides an easy process to think through what you need to achieve them.

Use these resources and tools to develop your plan, from goals to the specific steps to get you there.

Being Assertive



No matter how informed or how well-intentioned people may be, you are the expert on you.

No matter how informed or how well-intentioned people may be, you are the expert on you—what you need, what you want, the skills and capabilities you have. However, you're almost sure to have times when what you want differs from what your family or health professionals think is best for you. What do you do?

First, being assertive or self-confident is not a black-and-white characteristic. It's something most of us learn over time. And real confidence doesn't damage other people's dignity. One of our Peers described confidence as gentle, but insistent guidance. "You can be firm, but be kind. That builds relationships—that we all need—and, understanding and mutual respect."

Second, you need to become an expert on your injury or condition, what supports are available to you, such as finances, equipment—a whole range of factors.

With this information and opinions in hand from your advisors, and with support from organizations like BCITS, where you want to live is up to you (and the availability of housing and home supports that fits your needs).

Recipe for Assertiveness and Self-confidence

- ✓ **Learn** the facts about your condition or injury. Read, ask questions, talk to people with your disability living in the community. Become an expert.
- ✓ **Read** about or take courses in assertiveness, self-esteem or personal development.
- ✓ **Ask** for support from individuals and organizations with your move into the community. We provide many options in this Guide.
- ✓ **Develop** a plan, ask for what you want and persevere.

support and services

Relationships and support are important to all of us, and no less to someone who is living with a disability. There is a range of individuals and organizations who are here to help, advise and support you.

Family and Friends

When you are living with or adjusting to a disability, relationships with family and friends may need some special attention.

Two people with the same disability can respond to it differently and the same is true for families and friends. Some people may immediately support you by wanting to know about your disability, asking how they can help and generally engaging you about keeping your relationship strong. Other people may be frightened by your disability or be uncertain of what to do.

“My family just doesn’t talk about it,” said one of our Peers who uses a vent. “I see them a lot and I know they love me, but they just can’t talk about it. It’s just the way it is.”

Maintaining or strengthening your connections with people may be up to you—in the beginning at least. You will be in the role of an educator simply because most people have no experience of your disability. Be open about your disability, about how your life is changing and what you look for in your relationships.

Then, be ready for people to walk through the door you have opened—or not. Some people, including some family members, may never be there for you in the way you hope. Just keep communication open and they may come around as you show them that you are still the person they know and love.

And, enjoy the many people who will make the adjustment and stay connected with you.

Moving Home

Maintaining or strengthening your connections with people may be up to you—in the beginning at least.

If you're moving back home with your family, clear and unambiguous communication is crucial.

Your family may be welcoming you with open arms, which is wonderful. However, they may not fully understand what daily living with your disability will mean: your physical needs, having caregivers in the home, needed renovations, etc. You will need to communicate a real picture of living with your disability so there are no surprises, especially if there are children in the family.

Peers are Here to Support You

Our Provincial Respiratory Outreach Program (PROP) has a long-standing Peer Group: people who use ventilators, many of whom now live well in the community in various types of housing.

The group has now expanded its mandate and serves our Technology for Independent Living (TIL) clients as well.

And what do Peers do?

- ✓ They will provide a friendly and experienced ear if you need to talk to someone.
- ✓ They can tell you what they've learned and what their lives are like.
- ✓ They can introduce you to a network of organizations to find information you need.
- ✓ Our Peers have various disabilities, so if we can, we will connect you with someone living with your disability.
- ✓ And, whereas CARMA volunteers (see below) work only with residents of George Pearson Centre, our Peers will work with any of our TIL or PROP clients.



CARMA

The Community and Residents' Mentors Association (CARMA) is a mentors group based at George Pearson Centre. CARMA mentors meet with residents weekly; provide information and skills training for residents who want to move into the community; and, help with this transition. CARMA's activities and resources are available only to Pearson residents—whether they choose to remain living in Pearson or to move out. The mentor/resident relationship involves visioning (about the residents dreams, gifts, resources), personal support planning (strategizing around how to realize the vision), and discharge/resettlement planning (advising/assisting with the discharge process).

Organizations

There are community-based and government groups that provide independent living services and information. We have compiled a list of some of the most important organizations in the appendices of this Guide.

the discharge process

If you are in a care or rehabilitation facility now and want to move into the community, we hope you'll find many helpful steps and tips in this Guide.

The discharge process itself varies from facility to facility and, depending on where you are living now, BCITS may be able to work with you and the facility on a smooth transition.

For example, if you are a ventilator user, most care facilities know about PROP and will ask us to become involved in discharge planning. This is also true for people who are discharging from GF Strong Rehabilitation Centre. And, if you are currently at George Pearson Centre, a Peer from CARMA can support and advise you during your discharge.

Once you are a PROP or TIL client, we can help in many ways. We can help by:

- ✓ attending discharge planning meetings
- ✓ assessing your equipment needs, and
- ✓ doing in-home assessments to set up your technological needs.

And, once you are settled, BCITS has ongoing client services through our PROP and TIL programs.

Once you are a PROP or TIL client, we can assist with the discharge process by attending meetings, assessing your equipment needs and doing in-home assessments to set up your technological needs.

If you are not a BCITS client, you can apply to become one. You can learn more on our website about our services and becoming a client.

If you are not eligible for our services, we recommend that you contact a community organization that specializes in your disability, to find out what services and supports they have available to help you.

Your Priorities

More and more people, including our Peers, are proving that people can and do create good lives when needed supports are in place.

In 2010, discharge planning remains strongly tied to the medical model. Facility staff will usually be focussed on medical concerns around your ability to live independently.

Your health and safety are obviously crucial. However, it will be up to you—and your Peer advocate if you have one—to make the case for your other priorities such as independence, more control over your care and living choices, and so on.

Understanding the challenges of living in the community and having a plan to address them, will put you in a strong position. One of our Peers can help you prepare your plan.

Discharge Steps

Here are some key steps we recommend to ensure a smooth transition into the community.

- ✓ Connect with someone from our Peer group. They will help you understand the discharge steps, advise you, provide resources and/or assist you where they can.
- ✓ Gather information, like this Guide, created by experts in the community—not only information from medical or government agencies. You will need both.
- ✓ Think about where you want to live and in what kind of environment. And, think about your home support services: do you want to receive your care through an agency or would you like to use the Choices in Supports for Independent Living (CSIL) service model (see information in this Guide on CSIL)?
- ✓ Meet with a case manager from your local health authority. They are a key resource for information on transitioning into the community. They will also assess you and determine the number of home support hours you are entitled to through the Ministry of Health Services, Home and Community Care Program.

- ✓ Ask a trusted friend, family member or peer to attend discharge planning meetings with you.
- ✓ Develop your moving plan! Put together everything you've learned: your community resources and supports, and your goals. Go through your plan with a friend or family member, or one of our Peers.

Transition Support

There are many experts you can call on to help with your transition. Some will advise you, some will provide medical information and some will connect you with community services.

Here are some of the key professionals and their areas of expertise.

Doctor	GP or specialist: medical progress and details
Primary Nurse	assessment of needs to live independently, e.g., time/task analysis, supplies
Respiratory Therapist	provides information on your respiratory status, manages your equipment needs and provides therapy
Biomedical Engineering Technologist	PROP and/or TIL staff will customize technology to meet your specific needs, such as home controls, electronic safety and respiratory equipment
Speech Language Pathologist	communication aids
Case Manager	assessment of home support hours, identifying community resources
Social Worker	funding and applications for government/private programs, housing information
Occupational Therapist	helps select equipment, assistive technology, home renovation information
Physiotherapist	physical rehabilitation, equipment recommendations
Nutritionist	assistance for ventilator users who temporarily need a feeding tube

housing and care options

Home Support

Wherever you live or would like to live, your housing and the level of home support you need will be intertwined. If you are using a ventilator, for example, you will need a high level of care, so your housing options will need to take that into account.

Your Home and Community Care case manager is your first resource and will work with you to identify the types of housing available in your area and the care level they provide. Your case manager will also work with you on what will be needed to move back into your own home, including housing renovations, home support hours, and any costs associated with your services and equipment.

It's important to know that the phenomenon of people with a high level of disability living independently in the community is still fairly new. More and more people, including our Peers, are proving that people can and do create good lives when the needed supports are in place.

However, not everyone has caught up with this reality and some resistance remains, within the health system in particular. This Guide was created, in part, to give you some tips and tools to help shift these biases, if you encounter them.



Choice in Supports for Independent Living (CSIL)

CSIL is a ground-breaking program that began in BC in 1993. People with disabilities who qualify for home support hours can choose the CSIL service delivery option. Clients then receive funding directly from the Ministry of Health Services to manage their own home support. CSIL users are responsible for designing their own care plan, finding employees, training employees—everything to do with their own care. People who may not be able to fully manage their own care, can also qualify for CSIL through assembling a Client Support Group. CSIL has a very high approval rating with users because of the freedom and control they have over their care. Ask your case manager about CSIL.

Housing Types

The availability of accessible housing options for people with disabilities is partly dependent on government funding that shifts over time. However, here is an overview of housing types you can explore. CARMA, your case manager or BC Housing are good sources for information on current housing options in the area where you live.

Shared-Care Residences

One of the main challenges of community living for people with disabilities is securing funding for sufficient home support. Because of policies and funding limitations, people may not receive the ideal number of hours to comfortably meet their needs.

A creative approach that has spawned some facilities in BC is a shared-care model. In these buildings, each person has their own apartment, but attendants/home support workers are shared among the residents. This model works quite well for people who want independence and privacy, and the ability to share care resources with others with similar needs.

Group Homes

Community organizations in partnership with BC Housing manage groups homes, including homes for people with disabilities. These usually house about 10 people and provide shared care for the residents. Group homes are less expensive for residents, but there are also more limitations on privacy and flexibility.

Living independently

Some people choose to live in their own home by themselves or with their spouse or family. You will find ideas throughout this Guide on what you will need to know and do if this is the option you'd like to pursue.

To qualify for home support through Home and Community care, your personal care needs will be assessed and hours allotted to you. Then, your home support can be provided either through a home care agency or through the CSIL option that allows you to hire, train and manage your own home care workers.

Your case manager and/or a Peer can help you to explore housing options in your area and sources for supports, such as home renovation grants or equipment.



As Peers, we don't start from our experiences or our knowledge of services. We want to know what YOU want, what's important to you. Then we do our best to help you to get that, to provide information and resources to get what you want.

technology

Your discharge evaluation and planning will include a detailed assessment of the equipment and supplies you will need to live in your new home.

Your case manager will be experienced in this process and will help you—just remember that your needs guide the process. You'll want to brainstorm all of your daily activities and routines thoroughly, so you have a comprehensive list of everything you need.

BCITS Equipment

As we mentioned earlier in this Guide, once you are a BCITS client, we will work with you and/or your case manager to:

- determine your equipment needs through our PROP or TIL programs (for example, a ventilator or home control system),
- provide this equipment at no cost from our equipment pool,
- provide in-home set up and ongoing maintenance, and
- provide training on how to use and maintain your equipment.

BC Personal Support Network

In 2009, an exciting new community program began in BC to improve the provision of personal supports for people with disabilities, including equipment and assistive devices. There are many providers of assistive devices in BC, in both government and community sectors. However, finding them can be a complex and difficult process because there is no universal program.

Now, a number of BC community organizations have formed the BC Personal Supports Network (BCPSN). The Network is in the early stages, but once it is fully operational, it will coordinate community-based equipment and assistive devices service providers.

Here's how it works:

- ✓ Each Network Partner will help people with disabilities to develop a plan using a simple tool, like the Personal Strategy Tool in the appendices.
- ✓ Then, the organization will work with the client to find the supports they need to meet their goals.

Occupational therapists

Most BC communities have Occupational Therapists (OTs) working through the local health authority. The OT's job is to work with you to assess your in-home needs and direct you toward agencies or organizations that can supply equipment.

training and education

We've talked a lot about becoming an expert on your own needs. The more you know about your disability, independent living options, equipment and community supports, the more chance you will have of putting together a great plan for your transition.

Life Training

The Personal Development section in this Guide may be the most important "training" you can undertake. Becoming more sure of yourself, learning personal perspectives that empower you and developing positive ways to communicate will all help to build a personal foundation for everything you do.

BCITS Training

As a BCITS client, training on the equipment you loan from us is included in our services. Our Respiratory Therapists and Biomedical Engineering Technologists will take you through the steps of understanding, using and maintaining the equipment.

We also have PROP courses for family, friends and caregivers on use of our ventilators and other equipment.

Finally, we also can help you develop personal plans for your home support and for emergency preparedness.

In an institution, the needs of the unit may sometimes be more important than the person's needs. At BCITS, we want to flip that around.

conclusion

There are many challenges to living in the community with a disability. However, almost anything is possible given the right resources, information, skills and support.

We hope this Guide has provided you with some helpful places to start and ideas to consider when you want to put together your independent living plan.

Please also see the appendices for more information on BCITS and our services, and other resources and organizations that can help with your transition.

Here is a quick look at what we've covered in this Guide. And good luck!

Key Steps and Resources
Develop your vision • Think about your values and goals, and what you want
Be assertive • Learn how to be your own strong and informed advocate
Build relationships • Strengthen your support network of family, friends and Peers
Find support • Become familiar with the people and organizations that can help
Understand discharge • Know the key steps in the discharge process
Understand housing • Determine the housing and home support options you need
Obtain equipment • Define the equipment supports you'll need and find sources
Explore training • Take courses on your equipment and in personal development

appendices

Client Stories

We'd like to share the stories of two of our clients that illustrate many of the topics we've touched on in this Guide. The stories describe some obstacles our clients encountered, but they also provide examples of the skills and resources they called on to reach their particular goal, such as perseverance, developing allies and the power of a circle of support.

These cases are not typical. In many cases, people with disabilities transition into the community smoothly—and, Paul and Mary did eventually have “happy endings”. They are both living well in the community and are giving back as BCITS Peers.

Mary Margaret Lambert

Mary Margaret Lambert, who has muscular dystrophy, has been living in her own apartment for over 20 years. When the time came that she needed to have a tracheostomy and move onto a ventilator, there were some medical professionals who believed she could no longer live independently. So, Mary called upon her many personal and community resources to support her desire to live on her own.

“One day, my lungs failed,” Mary said. “I went into Burnaby Hospital, had to be trached and put on a ventilator. I knew that day might come eventually and, in a way, I was lucky because I had friends who used vents. I knew people were out there, happy.”

But, after she received her trach, the “system” started kicking in: some of the doctors and other professionals around her began saying that she couldn't move back to her home. A group home would be safer, they said, and better suited to her care needs. During this time, Mary couldn't speak because of her new trach, so she wasn't able to respond.

“Being an advocate, I also had my own ‘system,’” Mary said. “My brother was there a lot to speak up for me, when I couldn't. And, I had friends and attendants who knew me well and explained the kind of life I lived, how I valued being independent.

“The hospital staff started to know me and get a sense of who I was. This was really important: it created a foundation, a relationship and, because of that, they were invested. They began to go the extra mile for me to make things happen.”

But, after she received her trach, the “system” started kicking in: some of the doctors and other professionals around her began saying that she couldn't move back to her home.

The next step was to educate staff about her disability. “Medical staff always want to manage risk. Even though they were starting to be ‘on my side’, there was some apprehension because they hadn’t known someone with my kind of disability who had their own home and pretty strong ideas. They were more used to people who went along with the medical model,” she said.

So Mary stood her ground. She persisted in what she wanted, where she wanted to live and how she wanted to live. “Slowly but surely, staff started to see me as an expert in my own realm, whereas before they deferred to other ‘medical’ experts about what was best for me.”

“The hospital staff started to know me and get a sense of who I was. This was really important: it created a foundation, a relationship and, because of that, they were invested.”

Because of Mary’s involvement with various disability organizations, she also knew about independent living options. She knew that a group home wasn’t her only option: there were shared-care options, as well as a care option that would allow her to live on her own.

“I had lots of help and lots of people providing information,” Mary said. A staff person at BC Coalition of People with Disabilities really helped. She advised me on how to advocate for myself, acted as a go-between with the hospital and attended the discharge planning meetings when I couldn’t talk. BC Paraplegic Association helped me to keep my continuing care hours. PROP and TIL were a huge help. I had the support of the Peer Group; staff helped with my discharge; and a Respiratory Therapist really reassured me, calmed my fears about using a vent. She walked me through what to expect and how to live well with a vent.”

“I also took the vent training from PROP which also gave me lots of information and peace of mind. Burnaby Hospital also has training to help you transition out of hospital and that was helpful too.”

Also, an Occupational Therapist and Physical Therapist from Mary’s health authority worked with her to find the equipment she needed from a variety of sources in the community.

Paul Caune

Paul Caune had a truly “incredible journey” from living in a group home, to a hospital, to George Pearson Centre, to finally living in his own apartment. A series of events tested his resolve and his ability to find support for his desire to live independently.

In 2005, Paul, who also has muscular dystrophy, was unaware that his carbon dioxide level was increasing to poisonous levels. One day he was in the laundry room, and the next moment, he woke up in intensive care. And soon after, he was told he needed a tracheostomy.

For the next three months, Paul was in ICU adjusting to the new realities of his life. “Having a hole in my throat, needing a vent—these were all huge things and all kinds of opinions are coming at you from social workers, doctors, family.”

After a while, Paul was moved to a regular ward and the question of where Paul would live was discussed. He assumed he would go back to his group home and he made these wishes clear. A long series of negotiations began. Paul negotiated a place in another group home, he and his parents took PROP’s ventilator training course and, several months after going into the hospital, he was living in a group home.

All went well, until about six months later when Paul’s care worker asked the health authority for extra hours to manage Paul’s care on a permanent basis. The request was denied and, as a result, the group home said they couldn’t keep Paul as a resident. A week later, he contracted pneumonia and had to be hospitalized.

“So when the pneumonia cleared up, I had nowhere to live in the area I had lived before—and where I’d lived all my life,” Paul said. “The hospital staff began pushing [George] Pearson [Centre] as my only option.” Soon a spot in Pearson Centre became open, but Paul repeatedly said “no”. However, he finally agreed, knowing he would keep looking for another group home.

“While all this was going on, I had a lot of help at Pearson from CARMA. They advised me, and spoke with the service provider and the health authority. Finally, I said I was willing to move to another area of town if necessary to find an accessible place.”

CARMA continued to help in many ways. They suggested places he could apply to live, shared their knowledge and experience and, perhaps most important, they opened his eyes to other options. “Really, I was scared to live on my own; I just didn’t see this as an option. And CARMA has no agenda beyond mentoring people who want to leave Pearson. They were encouraging me from the beginning to live on my own.”

“Really, I was scared to live on my own; I just didn’t see this as an option. And CARMA has no agenda beyond mentoring people who want to leave Pearson. They were encouraging me from the beginning to live on my own.”

After a few tries, he found an apartment in Vancouver—28 months after he was admitted to the hospital the second time. With that in place, the discharge process began. In the end, Paul won a rare victory of 10 hours of care each day.

BCITS was involved with Paul's discharge and helped to settle him and his equipment in his new apartment. He has quite a unique care system, taking advantage of shared caregivers in his building for certain hours and his own caregivers for early morning and late evening. "I don't need someone all the time, I'm alone for most of the day, but this system gives me lots of flexibility."

"It was a big emotional barrier to overcome, to give up my home community, but I had to be realistic. Now, I have the highest quality of life I've ever had."

Publications

BCITS

Beginners Guide

This booklet looks at the key concerns new ventilator users have. Topics include: Adjusting to Change; Your Personal Support Network; Your Safety and Comfort.

Ventilator booklet: A Guide for people considering mechanical ventilation for their medical condition or disability

Topics include: How do I Decide? Advantages and Disadvantages; Independent Living; Frequently Asked Questions.

Balance

Three times a year, we publish our newsletter *Balance* which contains client stories, current news, equipment updates and tips, and information on our services and programs.

Online Resources

Stay tuned to our website (www.bcits.org) and our YouTube Channel (www.youtube.com/user/BCITS) for the latest BCITS resources and videos.



There are very few organizations that are as dedicated to their membership as BCITS.

CSIL Online Workbook: Your Guide to Applying for and Managing Choices in Supports for Independent Living

This three-module Workbook by BC Paraplegic Association is a how-to resource for people who want to know more about CSIL; people who already receive home support services, those who intend to apply for services or current CSIL employers who want support to manage CSIL. It is due to be published in late 2010. Contact BCPA at: (604) 324-3611 or www.bcpa.org.

Doing Whatever it Takes: Profiles of Peer Supported Transition from a Care Facility to the Community.

Created by BC Coalition of People with Disabilities' Community and Residents Mentors Association (CARMA), topics include: the Mentoring Process; the Transition to Community; Capacity Building Strategies; and Personal Stories. Read or download the profiles at: www.bccpd.bc.ca/publications/other.htm.

A Participation Model for a Personal Supports Program for People With Disabilities in BC

This report was prepared by the Provincial Equipment and Assistive Devices Committee (PEADC). The participation model is a new model that puts the needs of people with disabilities first in the delivery of personal supports, including training and education, equipment, and more. Read or download the report at: www.bccpd.bc.ca/publications/other.htm.

Your Perfect Right: A Guide to Assertive Behaviour

By Robert E. Alberti and Michael L. Emmons. With over 1.25 million copies sold, this is the assertiveness book most often recommended by psychologists. This manual is packed with step-by-step procedures, detailed examples, and exercises.

Organizations

Government

BC Housing

www.bchousing.org

BC Housing is the provincial crown agency that develops, manages and administers a wide range of subsidized housing options. BC Housing's Rental Assistance Program provides eligible low-income, working families with cash assistance to help with their monthly rent payments.

CSIL Choices in Supports for Independent Living

www.health.gov.bc.ca/hcc/csil.html

This Ministry of Health Services program provides funding directly to people with disabilities to manage their own home care.

CMHC

www.cmhc.ca/

Canada Mortgage and Housing Corporation has grants available to renovate homes to make them accessible for a person with a disability. These RRAP grants –Residential Rehabilitation Assistance Program for Persons with Disabilities–are available for home renovations for people who meet the eligibility criteria, including income level.

Government of BC, Personal Supports

www.personalsupports.bc.ca/

This website contains information about and links to programs that provide equipment and assistive devices or other personal supports to people with disabilities in BC.

BC Government Assistance Programs

www.eia.gov.bc.ca/pwd.htm

The Ministry of Housing and Social Development provides information on their services and programs for people with disabilities.

Handy Dart

www.translink.bc.ca/Transportation_Services/Accessibility/handydart.asp

The provider of custom transit services for the Greater Vancouver region.

Community-Based

BCITS

We are here to assist people with a high level of disability at several stages of the discharge process, including when they are living in the community.

Our services flow from our two main programs: the Provincial Respiratory Outreach Program (PROP) and Technology for Independent Living (TIL). PROP is a comprehensive program for people who need to use a ventilator; TIL provides communication devices and devices to control various electronics in a person's home.

We take a client-centred, comprehensive approach to serving our clients. More about our mission and our services can be found throughout this Guide and also on our website at www.bcits.org.

We are also the hub of the new BC Personal Support Networks in BC. See the Technology section of this Guide or contact us for information.

For information on how to become a BCITS client, please contact our office (see page 2) for an application form or visit our website: www.bcits.org/howtoapply.htm.

BC Coalition of People with Disabilities

BCCPD has a one-to-one advocacy program that assists people with disabilities to access benefits and programs they are entitled to, including medical and health-related benefits. Various other programs, and information and referral are also provided. Home page: www.bccpd.bc.ca. Individualized Funding Web-Based Resource Centre: www.bccpd.bc.ca/programs/individualizedfunding.htm. Phone 604-875-0188.

BC Paraplegic Association | Peer Program

The goal of the BCPA Peer Program is to provide social and educational opportunities for individuals living with a spinal cord injury, their family members and their friends. A Peer Mentor can provide personal support and assistance which may involve anything from discussing personal challenges they have met and overcome, to passing on specific information about community resources and services. Visit www.bcpa.org/bcpa.aspx?id=101. Phone 604-326-1237.



We put together our clients' needs with our staff's creativity, and find ways to help people live as independently as possible.

BC Personal Support Network

This network of organizations was established to improve access to personal supports for people with disabilities—everything from equipment and assistive devices, to sign-language interpreters and attendants. They use a person-centered approach that begins with a person's goals and offers assistance to find the supports to reach them. Go to: www.bcpsn.org for more information, including how to contact participating Network Partners.

Choice in Supports for Independent Living (CSIL)

The Association of CSIL Employers (ACE) is a new group of people with disabilities who use the Choices in Support for Independent Living (CSIL) program. The purpose of ACE is to form a collective or common voice around issues affecting the CSIL program. ACE is in the development phase, but will soon be a resource to share information and provide peer support. Email ace@csilbc.com.

Disability-specific Organizations

There are also many organizations in BC that serve people with a specific disability, such as cerebral palsy, spinal cord injury or muscular dystrophy. They are an excellent resource because they understand their members' particular needs and have often developed resources tailored to their members' needs and interests.

Personal Strategy Tool

This tool is used by the BC Personal Supports Network to help clients problem-solve around specific goals and what you need to reach them. It begins by asking you about a goal, such as “I want to move back home with my family”. You then answer three questions to identify problems and solutions.

It’s a simple client-centred tool, starting with what’s important to you. You can use the tool to help you brainstorm practical steps toward any goal, from moving into the community to finding a scooter.

You can use it on your own or, if you live in BC, you can contact the BC Personal Support Network and ask someone to assist you with your particular solutions .

Here are the three questions and an example.

1. What things do you wish to do in your home or community?
2. What is stopping you from doing these things?
3. What do you think you need to help you do these things?

Example of Answers

Question: What things do you wish to do in your home or community?

Answer: My goal is to move back home with my family.

Question: What is stopping you from doing these things?

Answer: I can’t get in and out of bed by myself and my partner has a bad back.

Question: What do you think you need to help you do these things?

Answer: I need some sort of lifting device similar to the one they use in the care facility.

turning point

a guide to community living for people
with a high level of physical disability

BC Association for Individualized Technology and
Supports for People with Disabilities

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