

carma



Community and Residents' Mentors Association

Doing Whatever it Takes

Profiles of Peer-Supported Transition
from a Care Facility to the Community

2003



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Cover photo

Left to right: Pat Forget, CARMA Steering Committee Member; Heather Morrison, CARMA Leader; Gayle Morton, CARMA Transition Assistant; Joseph Terriault, Interdependent Consulting; Taz Pirbhai, CARMA Leader; Paul Gauthier, CARMA Leader.

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Dedication

Mary Williams
1951 - 2001

This anthology of stories about CARMA's peer-supported transition of George Pearson residents to the community is dedicated to Mary Williams.

As a former George Pearson Centre resident, who made her own struggle to leave the facility and establish a life for herself in the community, Mary was one of CARMA's most devoted mentors. She gave of herself unselfishly and was often supporting as many as four residents at a time during their crucial moments of need.

Mary's community life was a distinguished one. She was a founder of the DisAbled Women's Network Canada (DAWN Canada); an executive member of LEAF, the Women's Legal and Education Action Fund; a human rights advocate; and, at the time of her death in 2001, the President of the BC Coalition of People with Disabilities. In her speech as a 2001 *Courage to Come Back Award* winner Mary said, "There is life after disability: I'm not my spinal cord injury and I'm not my wheelchair. I'm still Mary. I have a great quality of life—not just a good one but a great one."

Mary's life was an example of what can happen when people with disabilities come out of institutions and are able to share their gifts with the world.

Preface

Someone told me a story about growing up with her best friend in the early 1960's. "I used to be over at her house all the time," she said. "I practically lived there sometimes, and I never knew that she had a sister with a disability who lived in a back bedroom. You know, I never saw that bedroom door open."

A generation ago, it was accepted that people with disabilities would live out their lives in institutions or behind the four walls of a family home. Although our society has made great strides in increasing the accessibility of public spaces and supporting the goals of people who are wheeling around the world, there are still far too many people with disabilities living in care facilities of one kind or another. Most of the time they are there "for their own good" out of a common belief that people with severe disabilities are safer in a facility. Sometimes they are there because their social and community supports have broken down. Only rarely are they there because they have made the clear choice to be there.

CARMA was inspired by people with disabilities who had lived in George Pearson, a large care facility in Vancouver, BC, and who had made a personal struggle to move out and establish themselves in the world outside. What made the difference for them was, not only their determination, but also the wisdom, experience and encouragement of the people who had gone before. CARMA's founders resolved never to forget the residents they left behind when they resettled in the community. They envisioned a network of peer support that would offer hope and the opportunity for Pearson residents to make choices about their lives.

Fortunately, the BC Coalition of People with Disabilities and the Sharon Martin Community Health Trust Fund (SMART) of Vancouver Coastal Health supported the vision of CARMA's founders. Their partnership has enabled the involvement of many more partners like the BC Paraplegic Association, the Multiple Sclerosis Society of BC, the Rick Hansen Neurotrauma Initiative Community Fund, Neighbour Gardens Society, and the Muscular Dystrophy Association in helping residents of George Pearson Centre link to the larger community and, in some cases, to resettle into it.

I wish I could say that people with disabilities now feel secure in their ability to make choices about how and where they will live. Unfortunately, each change in government policy or news of public budget deficits is greeted fearfully by people with disabilities who need support to live the lives they choose. They never feel secure in their human right to life, liberty and the security of the person. If the challenge for the last generation's policy makers was to get people out of the back bedroom, then the challenge for this generation's policy makers is to ensure that people with disabilities really can be first and foremost citizens, not patients or clients.

Christine Gordon, BC Coalition of People with Disabilities

Introduction

In March 1998, a new program opened in Vancouver, British Columbia called the Community and Residents' Mentors Association (CARMA).

CARMA was conceived by former residents of George Pearson Centre—a large residential facility for people with physical disabilities. It was a response to some of the basic needs of people living in institutions: to feel choice and agency in their own lives, to feel worthy of relationships with others, and to learn—or relearn—how to nurture these relationships. The CARMA founders knew through their own experience, and as disability advocates, that these basic needs are often casualties of institutional living, creating a pall of helplessness and hopelessness. They hoped not only to lessen these dehumanizing feelings, but also to enable community living for all residents who desired it.

The CARMA project is sponsored by the BC Coalition of People with Disabilities and funded by the Sharon Martin Community Health Trust Fund (SMART) of Vancouver Coastal Health (*please see the appendices for more information*). The purpose of the SMART Fund is to support community based health promotion initiatives which enable people in their communities to gain control over the resources for their health. This purpose is a perfect fit with our objectives because people with disabilities who live at Pearson Centre are isolated and have lost control over these resources.

In this report, we would like to offer a profile of CARMA, a group we have found to be challenging and inspiring in equal turns. We will take readers through two main sections:

- a walk through CARMA's background, philosophy, capacity building strategies and the factors enabling transition to community; and
- interviews with four CARMA participants who have made this transition.



Who we are: CARMA's Project Leaders

Paul Gauthier, a former group home resident, has worked with CARMA as a consultant for several years. One of his main roles, and joys, is to help people reach their goal of moving to community. He brings a wealth of experience in transition planning, home support, long term care and the various home support options, from the Enhanced Consumer Participation Model to Choices in Support for Independent Living. Paul is also a skills trainer for living in community, from navigating the discharge process, to living independently, to being a good employer. Paul is known for using his persistence and diplomacy to help people obtain whatever they need to live independently.



In 1981, **Heather Morrison** went into respiratory distress as a result of Muscular Dystrophy. After a stay in intensive care, she was sent to the respiratory ward at George Pearson Centre. She was overwhelmed at the changes in her life, but with the tremendous support of her family, she not only survived, but was able to follow her dreams again. Two years, ten days and an hour and forty minutes later, Heather left Pearson to live in her own apartment. As a CARMA project leader, she enjoys enabling residents to follow their dreams—living in Pearson or in the community.



Taz Pirbhai, a co-Founder of CARMA, graduated from the University of British Columbia in the early 1970s with a BA and BSW. She has worked extensively with people with disabilities in a variety of settings and is a firm believer in self-determination. Her strong commitment to helping residents of Pearson transition into the community comes from her own experience living at Pearson. Taz is currently living independently in her own apartment in Vancouver's Coal Harbour, using the Choices in Support for Independent Living program.



Pat Forget is a resident of Pearson who sits on the Residents' Council, as well as on the CARMA Steering Committee. She spearheaded the development of the Pearson family room and is actively involved in the building of the cob house on the facility grounds. Pat and her husband Joe are avid model train enthusiasts. Their dream is to drive across Canada in a camper van.

CARMA's project leaders are supported by a host of mentors who live both at Pearson and in the community. Mentors move in and out of Pearson residents' lives as they are needed to bring encouragement, information, companionship or moral support.

First steps

The CARMA founders articulated the essence of their vision in this way:

- to become a presence at George Pearson Centre for residents; to offer support, information and friendship,
- to provide peer support for residents who wish to explore the transition to community living,
- to increase residents' opportunities to learn about their choices and develop new skills and abilities, and
- to evaluate the effects of peer mentoring on residents and on deinstitutionalization.

From the beginning, CARMA has been grounded in the concept of mentorship. People with disabilities living in community, some of whom had once lived in Pearson themselves, were defined as mentors for people still living in Pearson. We have found that people living independently are very skilled in managing their care and creatively using their resources, so they in turn are an excellent resource for residents of Pearson.

The mentors have developed these key activities and approaches:

- Running the CARMA office, established at Pearson in 1998.
- Holding regular information meetings at Pearson.
- Touring the wards three times a week to meet and talk with residents, including each new resident.
- Providing information, options and skills training for residents interested in living in community.
- Developing capacity building strategies to enhance self-confidence and relationships among residents.
- Helping residents in their transition to community, often taking the place of family when there are no family supports

Community living is a cherished goal for many Pearson residents, but not all. CARMA's activities and resources are equally available to people who choose to remain in Pearson.

Community living is a cherished goal for many Pearson residents, but not all. CARMA's activities and resources are equally available to people who choose to remain in Pearson. These residents benefit from their relationships with mentors and from our capacity building strategies which are described in a later section.

The mentoring process

The heart of the CARMA program is the resident/mentor relationship. We have come to see three stages within this relationship continuum:

- visioning
- personal support planning
- discharge (resettlement) planning

3 major stages

- ▶ visioning
- ▶ personal support planning
- ▶ discharge (resettlement) planning

Visioning

After the first steps toward building self-esteem and trust with a mentor have been made, the process of visioning begins. This is a kind of life brainstorming on the person's goals, dreams, gifts, skills and resources. In the safety of an established relationship, the person is encouraged to paint a picture of where they are now and where they would like to be.

For some at Pearson, this means improving their quality of life at the Centre. For others, it means forming a plan to transition to community.

Visioning is an ongoing process with CARMA mentors, both in planning and in practically helping to achieve the elements of the person's plan.

Personal support planning

As mentors learn about the resident's hopes, they begin to help with planning. This can take the form of one-to-one support or strategizing about various activities, both at Pearson and in the community, that can help the person build on their gifts.

Heather Morrison said, "In institutional life, choice is an alien concept. Meals are served at a certain time, you don't say when you want to eat. You have a shower on Thursdays, you don't just ask for one. So the amount of choice and freedom people will have when they live on their own takes some getting used to. People need to relearn their own needs and to ask for what they want. But once they get it, boy, it's an exciting thing to watch."

CARMA assists residents with detailed personal support planning, so they can understand what supports they will need to accomplish their goals. For example, will they need a power wheelchair? How will they use a telephone? When do they need personal assistance and for what activities?

Like visioning, personal support planning is an ongoing process. A resident may begin with one relatively small goal (for one resident, this was to be able to

wear pants), but it progresses (this same resident now lives in the community and has a volunteer job). CARMA mentors have learned that achievement of any goal promises the making of another one.

Discharge (resettlement) planning

This phase of the mentoring process can be intense. As soon as a resident secures housing, the discharge process can officially begin. Once rent needs to be paid in the community, there is usually a frantic flurry of activity to get things resolved as quickly as possible. This is the point at which the line between mentoring and advocacy begins to fade.

CARMA mentors support residents to speak for themselves and never attend a discharge meeting unless the resident has invited them. However, mentors who know the ropes of community living are able to use their networks to great advantage. For example, they know when accessible housing becomes available before the rest of the world does, they know how to find and train personal support workers, or where to get a bath slide. This inside knowledge and experience is an important contribution to the discharge planning process.

The most important part of the discharge planning process is keeping up the momentum. Mentors work closely with the resident to keep them focused on the tasks and encourage the discharge planning team to do the same.

“At this point,” said Paul, “there can be a different group of staff at each discharge meeting. That can be frustrating, going over the same ground, but each discharge then becomes an opportunity to share a positive approach with staff.”

CARMA mentors also know many of the common objections staff can have around people exploring discharge and know how to keep them from stalling the process. For example, people with MS often have difficulty swallowing and this has been brought up in several discharge meetings. We now address this issue directly at the meetings and how the resident has planned for it.

We also offer one-to-one and group skills training with residents: both for community living and for the discharge process itself.

Like every other part of CARMA's work, discharge is guided by the individuality of each person: their strengths, their hopes, their needs. Though finding all the necessary supports for living in community remains a challenge, a variety of support options are thankfully emerging to dovetail with these kinds of individual differences, such as Choices in Support for Independent Living (individualized funding for home support), client support groups and client-centred community living organizations, such as Spectrum.

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The transition to community

Entry *into* a care facility is usually a one-way street: there is no road map for moving *out*. Each individual confronts the challenge of discharge in a unique way and CARMA's role with each person is therefore unique.

"One of the biggest lessons of successful transitions has been that blueprints don't work," said Heather Morrison. "If you use a cookie cutter approach to someone's discharge, it will fail."

Whatever form each person's plan may take, moving from an institutional facility to community living holds challenges which fall generally within three basic areas:

- personal/interpersonal
- institutional
- systemic/community

Personal/Interpersonal

In the Introduction, we touched upon the basic human need of relationship and the all too common erosion of relationships in institutional living. The extent of this problem was a surprise even to the CARMA mentors who set out to build relationships with residents and share information on community living.

Over the years, the mentors discovered that, first, relationships simply cannot be forced and, second, that community living is perceived as a remote possibility indeed when a person has few opportunities for developing self-awareness or self-esteem. The mentors found, with some residents who had been institutionalized for many years, that we were moving too quickly—that forming relationships with people who have few or no opportunities for socializing and self-expression

is extremely difficult. The effects of institutional life numb a person's ability to recognize or express their own needs.

We therefore began to focus on individual gifts and capacities, and developed a number of strategies to build on them. Some of these strategies are described in a later section.

This approach, along with the strong social and emotional support provided by mentors, began to bear fruit as residents had opportunities to express themselves and interact with

factors in success

personal/interpersonal

knowledge/information
determination persistence
self-esteem
personal support

others. With these fresh beginnings of self-awareness and self-esteem, came the possibilities of choice and, ultimately for some, the risk-taking that is part of transitioning to community. More residents came to see living in community as a tangible possibility, instead of an unrealistic dream.

“For people who have been living in an institution, some for 20, 30 years,” said Paul Gauthier, “they have no experience with the daily management of their lives: what it means to live in community, spend money, prepare meals. You can’t make any assumptions; people need the confidence, the skills and the support to make it work.”

Support is crucial to helping people maintain their determination and persistence. We have found the magic combination to be determination and support: a person who has one, but not the other, will not make a successful transition.

Institutional

“Traditionally, residents who want to resettle in the community have met with some resistance from the institution itself. There was no culture of discharge at Pearson Centre,” said Taz Pirbhai. “But that’s changing. Now there are more discharge meetings and CARMA plays an active role in supporting residents at these meetings. Walls don’t come up right away when someone mentions moving out into the community.”

It was clear to CARMA from the beginning that the blade of institutionalization cuts both ways, wounding both the person in care and the caregivers. The possibilities of genuine independence, or even selfhood, for a person with a significant disability are entangled with ideas and myths around capability, decision-making, self-worth, risk-taking, support needs, financial concerns—and the list goes on.

Our experience has been that both residents and staff are initially very fluent in explaining why transition won’t work, and need a great deal of support and information to realize it can and does work. We therefore have both groups in mind when we plan and carry out our vision.

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factors in success

institutional

offering positive views of disability

creating a culture of discharge

breaking down myths of disability=incapability

inviting community into discharge planning

Through our knowledge of the needed community supports and our participation at discharge meetings, CARMA helps to create the bridge that carries the person from an institution to life in community. These phases are discussed in the section below.

At Pearson, CARMA has been like water dripping on a rock—slowly but surely making its mark through persistence and a strong vision. We are now an established presence at Pearson. Our independence from the institution’s bureaucracy has enabled us to bring a fresh perspective and to create new opportunities and resources that might not otherwise have been available.

“The presence of a strong corps of mentors at Pearson has provided the staff with positive role models of disability,” Taz said. Perhaps the most powerful models are the people who transition to community. Many were told by staff that “they would be back,” that community living would not work for them. But, once they left, they never looked back.

Systemic/Community

Once a resident has made the decision to leave Pearson, and once Pearson is on side, CARMA mentors embark on another challenging leg of the journey. A web of support for a transitioning resident must be built, including:

- affordable and accessible housing
- adequate home support hours
- income support
- equipment and supplies
- furnishings and supplies for a new home
- finding medical professionals
- finding community/social activities

There is no generic support planning or generic life skills training. CARMA’s motto has become, “do whatever it takes,” to make a transition work for a particular individual.

We use the unique skills of each person on the CARMA team to weave together this support web. This is where our experience and inside knowledge can really come to fruition in making the practicalities fall into place.

Again, the keys to a successful transition to the community are person-centred planning and individualized supports. There is no generic support planning or generic life skills training. CARMA’s motto has become, “do whatever it takes,” to make a transition work for a particular individual.

If the resident asks for help, CARMA will provide practical assistance with any or all of these needs, as well as providing continuing support as long as it’s needed. In addition, thanks to the Community Reintegration Project, sponsored by

the Rick Hansen Neurotrauma Initiative Community Fund, CARMA is able to provide specialized supports to people with spinal cord injuries and neurotrauma.

Through our association with the BC Coalition of People with Disabilities, CARMA has an ongoing opportunity for advocacy on the needs of people who are seeking community living. The systemic barriers faced by Pearson residents are much like the barriers encountered by all people with disabilities. The difference is one of degree. Institutionalization takes its heaviest toll on self-esteem, support networks and decision-making skills. These are the ingredients that CARMA focuses on with each Pearson resident while attempting to do the advocacy which will reduce the barriers for all people with disabilities.

factors in success

systemic/community

person-centred planning
 support network
 staff education
 home support
 individualized support
 financial support
 equipment & supplies
 affordable, accessible housing

Capacity building strategies

In this report, we have described the isolation and powerlessness that often marks a person living in an institution, and how these responses can prevent the seeds of relationship from taking root. As we came up against this reality time and time again, we began to develop strategies for capacity building.

We asked ourselves what we could do to enable people to know or rediscover their own needs and personal resources so they could achieve desired change. We began to plan activities where residents could build self-confidence, develop skills, interact with others and have opportunities for friendships. Over the past few years, we have organized a range of events within Pearson Centre, as well as other activities linked with the broader community. Here are some examples.

- In 2000, CARMA leaders worked with residents on a Homecoming Festival at St. George's Place. Present and former residents worked with the church auxiliary to plan games, demonstrations and a bake sale. They sold tickets and solicited donations for a raffle. More than \$1,000 was raised for the purchase of household goods for Pearson residents.
- The Boccia Club has now been flourishing for about three years with CARMA leader, Paul Gauthier, training Pearson residents. The Club has become connected with the various Lower Mainland boccia clubs established by people with disabilities and offers opportunity for wide social connections.

Pearson's recreation department has now taken over coordination of practises.

- One of residents' favourites is the gardening project, undertaken with the community-based group Neighbour Gardens. This unique project began with one CARMA leader whose passion for gardening was shared by some residents. They began tending plants, flowers and bird feeders. From this simple beginning, and with the help of Neighbour Gardens, we now have a garden, including raised beds, outside Ward 5 at Pearson. Pearson residents also participated in building a community garden in a backyard in the neighbourhood. Then they went on to plan and build a prototype cob house (made of mud and straw) on the Pearson grounds. This partnership with Neighbour Gardens has forged new relationships among those working on the garden and also enabled us to link with a whole other network of community mentors.



Boccia Club members, from front to back: Hanif, Lenny, Randi, Dan, Stewart and George

We asked ourselves what we could do to enable people to know or rediscover their own needs and to achieve them.

- CARMA also facilitates the Pearson Residents' Council which hears residents' ideas and concerns, and works to improve the Pearson environment. In 2003, for example, CARMA was instrumental in helping to achieve one of residents' long-held dreams: a self-contained family room for use by visiting family and friends, as well as residents.
- Over the past few years, residents had told us they were tired of the unattractive appearance of Pearson's resident entrance. Especially for those who call Pearson home, they wanted a warmer reception for their visitors and for themselves. With the help of residents, CARMA undertook a major beautifying and greening project: we asked Pearson administrators to remove laundry trolleys; organized flower planters and barrels; and installed a trellis and sitting bench.
- Outside of these specific programs, CARMA leaders also work with residents to uncover their individual gifts and capacities. This depends upon a good match between mentor and resident. For example, one resident has been encouraged to pursue painting and the project leader has facilitated finding art supplies and connecting to other artists. Another resident is interested in music. CARMA obtained a Walkman and music tapes, and does regular tape swaps with him to broaden the variety of music available.



Neighbour Gardeners Ava and Steve at work

Anthology

CARMA's real story lies in our participants' lives. Four individuals agreed to share some of their experiences, about themselves and their new lives in the community—and about what CARMA has meant to them.

Nancy McQuaig

This is a genuine "before" and "after" story.

For Nancy McQuaig, March 15, 1999, represents no ordinary anniversary. It marks a turning point in her personal life—the day she moved out of George Pearson Centre and into her own apartment on the West Side of Vancouver. Nancy, diagnosed with Cerebral Palsy when she was a year-and-a-half old, first moved into



Pearson when she was 18. Apart from the odd day trip and her weekly church attendance, she lived there continuously for the next 29 years of her life. The ebb and flow of her daily routine was defined by other people.

A communication board paired with a Litewriter assists Nancy to communicate. "It was noisy there," she said. "There was no privacy and not much freedom."

There were "BM (bowel movement) days" and "bed times." There were rules about wheelchairs: you could only get into your wheelchair once a day. If you got tired or uncomfortable and asked to be put back to bed, that was it—you stayed on your back until the following day. Most residents got to take a bath once a week.

While at Pearson, Nancy rarely went out. Apart from her weekly church trips, she usually stayed on the hospital property. She couldn't do her own shopping, so her mother bought her clothes. If her parents came down from the interior to visit her, they needed to stay with friends or in a hotel.

But this is the time After.

Now, Nancy lives in her own two-bedroom apartment in Vancouver. The complex, called St. George's Place, is non-profit housing made possible by the donation of the land of St. George's Anglican Church. Her new home is clean and comfortable. On her balcony, Nancy has placed flower boxes and pots that support a colourful collection of geraniums, petunias and pansies. It's the best-looking balcony in the complex.

Now, Nancy gets up when she wants to, usually after eating breakfast in bed. She also takes a bath whenever she likes—generally every other day. If she wants to take an afternoon nap, one of her personal care attendants will help her to get into bed, and then back up into her wheelchair again. Not only does she continue to

attend services at her favourite Baptist Church, but on Thursday evenings, she hosts a weekly bible study group in her living room.

Now, Nancy goes out every day. Her routine varies according to her own whim and pleasure. She and one of her attendants, like Lena, might take one of Lena's three dogs to Douglas Park, or they might decide to take the SkyTrain to one of Greater Vancouver's many malls. In fact, it is probably fair to describe Nancy as a "mall rat."

Now, when her parents or her sister Margaret come into town, they stay as welcome guests in Nancy's own home. Her brother Bill is happy to pop by to fix her computer or deliver a box of fruit from their parents' home in Summerland.

"At Pearson, Nancy wasn't able to spread her wings very well," said CARMA's Paul Gauthier. "The difference is night and day."

There was a time "before" Pearson too. The third of four children, Nancy was born in Summerland, in the interior of British Columbia. It was a childhood filled with sunshine, as she basked in the warmth of a loving family and supportive community.

Nancy's elder sister, Margaret McQuaig, described Nancy's CP diagnosis as both "a shock and a relief." The entire McQuaig family determined to deal with Nancy's disability by participating in life together with her as fully and completely as possible. "All our lives, our goal was to keep Nancy at home and out of institutions," said Margaret. "There are people who want to keep people safe. Our family are risk-takers. We'd take her swimming and she'd almost drown, then she'd want to go back in."

At first, it might seem surprising to learn that it was Nancy herself who decided to move into Pearson. But as Margaret pointed out, when Nancy was 18, all three of her siblings had already left home. So, Nancy decided that it was time for her to do the same.

But the transition to life in an institution was hard. "I was very sad when I went to Pearson," said Nancy, "I missed my family." And her family missed her too. "It was an awful time," said Margaret. But with courage and what Margaret describes as "tremendous tenacity," both Nancy and her family adjusted to the changes. As the years turned slowly into decades, Nancy lived her life as well as she could within the confines of institutional life.

But Nancy knew there was more to life than the routines that were available to her at Pearson. She indulged in a short period of hope about living in community when she put her name in to become a resident at Noble House, a False Creek assisted-living



"All our lives, our goal was to keep Nancy at home and out of institutions. There are people who want to keep people safe. Our family are risk-takers. We'd take her swimming and she'd almost drown, then she'd want to go back in."

residence. But her needs were assessed as being too high, so she was turned down.

Enter CARMA.

Nancy was old friends with Taz Pirbhai and Mary Lambert, two former Pearson residents who already lived in the community. In the spring of 1998, Taz and Mary had just founded the CARMA project, and Nancy became one of the first Pearson residents to be served by the project.

It was a tall order to secure equipment, housing and, the biggest hurdle, home care hours. "Nancy was one of the first people with her level of disability to move out," said Taz. Putting together a complete package required "a lot of negotiation" which would have been difficult for Nancy alone.

Paul Gauthier used his special talents to patiently and persistently overcome bureaucratic hurdles. Paul, Taz and Mary worked together with Nancy, exploring options and helping Nancy to visualize life outside of Pearson. Throughout, the CARMA team let Nancy come to her own conclusions. "CARMA pointed out alternatives, but Nancy made the final decisions," said Taz.

Twenty-nine years after Nancy first decided to move into Pearson, she finally moved out. She now has her own address.

After almost thirty years in Pearson, this was a challenge. "Nancy had a huge learning curve," said Paul. "She has more self-esteem now, she is not as scared to make decisions and she has learned how to communicate better."

The entire process took about a year. Paul said that Nancy, remembering previous rejections, was "scared of another failure." While Paul worked the system, Taz and Mary provided encouragement and moral support. In the end,

Paul was able to convince the Vancouver/Richmond Health Board to allow Nancy sufficient support hours to meet her needs. Because Nancy was using the Enhanced Consumer Participation Model (ECPM), Paul helped her in recruiting, interviewing and hiring prospective attendants, one of whom is Lena, who now works with her four days a week. Finally, everything was in place.

On March 15, 1999, it happened. Twenty-nine years after Nancy first decided to move into Pearson, she finally moved out. She now has her own address.

"It's been fantastic!" said Margaret. "I've never seen her look as relaxed and content about her life."

Nancy loves her new life and is grateful to all those who helped, particularly CARMA. "Without CARMA," she said, "it would have been impossible to move."

The key to this success? The answer, of course, is Nancy herself.

"She has been the most influential person in my life—without exception," said Margaret. "She's been a tremendous inspiration to people."

Richard Long

"I have a reputation for being difficult," said Richard Long, smiling slightly. You have the impression he doesn't mind the label too much. "But I learned that, if I take my time, eventually, people come around. I'm patient." His "difficult" requests were sometimes more than George Pearson Centre could easily accommodate, but now that he lives at Creekview Housing Cooperative his wishes are more easily fulfilled.

It has been almost 20 years since the day Richard was first diagnosed with Multiple Sclerosis (MS). Since then, his life has been marked by change: from living in his own home, to living in hospitals, to time in George Pearson Centre, and finally to living at Creekview in Vancouver's False Creek.

Looking back, Richard is still surprised at how little some professionals and staff knew about genuine independent living for people with his type of disabilities.

"At the time, Queens Park Hospital staff didn't know anything about what was out there for community living. One social worker suggested I go into a seniors home," he said, shaking his head. "Even at Pearson, the discharge director didn't know anything about Creekview. He knew the phone number, but nothing else."

So, he had to be resourceful, find allies like CARMA and be persistent. "When I was in Pearson, I heard rumours about a great place for people in my situation," Richard said. Other residents talked about Creekview in almost reverential tones.

After looking into his housing options, Richard contacted Creekview just when a vacancy became available. "The previous tenant was kicked out because of 'sex, drugs and rock and roll'. I was lucky to get in," Richard said.



Once Richard knew he was accepted at Creekview, CARMA launched into action. One day, CARMA volunteers arrived with boxes to pack up his belongings. "They gave me the feeling I wasn't alone. They supported me through my efforts to leave the hospital. I didn't realize how much they were on my side." He smiled as he remembered Heather Morrison

coming by often with chocolate and candies. "Apart from bringing us junk food, I wasn't sure what she was doing at first. Then I realized she was helping people who wanted to leave Pearson."

Taz Pirbhai said that, "Richard is an articulate person and he was used to advocating for himself. So CARMA's role with him was different." CARMA shared some of the lessons they'd learned through assisting other residents to move out: the best ways to make his case for discharge, anticipating objections, helping with practicalities, such as equipment and household items, and so on.

For some people, Pearson becomes home. For others, like Richard, it never did. He wanted to live in community and, for him, the difference in independence has touched every corner of his life. "Creekview isn't an institution, it's my home."

Richard shares a sprawling apartment in the False Creek cooperative with five other men. Each has their own room, plus a shared kitchen, living room, large meeting room, two extra guest rooms for visitors and family, and large outdoor balcony. It is an expansive, welcoming space with views of False Creek park. The rent for Creekview residents is subsidized by the Canada Mortgage and Housing Corporation (CMHC). Long-term care funds go directly to a pool for residents' 24-hour home care and home support staff.

Richard and his roommates share the expenses for basic groceries, with each person buying their own specialty items. "I find amazing prices on the Internet," Richard said with enthusiasm. "Like filet mignon and the freezer I keep it in. It saves me so much money, I can eat great."

And, he loves Granville Island's vibrant atmosphere. "Every day, I have a route I follow, people I see. I met Adrienne Clarkson once." He pulled out a copy of The Creek newspaper with an article he wrote on meeting the Governor General. And, years ago, Richard was an elementary school art teacher, so he loves to visit the Island's Emily Carr Institute of Art and Design.

The quality of care is also better: from meals to showers to simply having more control and choices around his care. Richard believes that Pearson staff do all they can within the constraints of an institution. "It's not as if the Pearson staff don't care. They care a lot about what they're doing," he said. "But, when I wanted to leave, they were upset. It's as if they thought I didn't like them or was rejecting their care." Rather than being critical of Pearson Centre, Richard simply appreciates the freedom he has now.

CARMA remains a presence in Richard's life, volunteering advice and practical support when he needs it. "Gayle [Morton] helped me arrange papers in my



"I've learned that when you do something for yourself, you're not being selfish because others can follow you."

room. And she accompanies a friend of mine from Pearson who comes here to have lunch.”

“I’m lucky that I knew my rights and I was determined, persistent.” After a minute looking out the window, Richard said quietly, “If I’d stayed in Pearson another year, would I still have those qualities? I don’t think so.” He recognizes that not everyone has those qualities. He believes that support and more education are needed to help people living in institutions to build self-esteem and create awareness of choices.

“My friends have noticed a huge improvement in my intellectual and emotional well-being since my move. They say that CARMA saved my life and I don’t argue with them.”

Aware of his part in the disability community, Richard sees himself both as a leader and a follower. He launched human rights cases against Canada Post and 7-11 outlets for inaccessible locations. “I don’t live in Burnaby any more, but there are curb cuts there for other people now because I asked for them.” And, he speaks with great respect of the men who lived in Pearson’s Ward 7 years ago, like Walt Lawrence, who first had the idea of creating Creekview. “I’m here because of them. And I’ve learned that when you do something for yourself, you’re not being selfish because others can follow you.”

“My friends have noticed a huge improvement in my intellectual and emotional well-being since my move. They say that CARMA saved my life and I don’t argue with them.”

Joanne Gaudreau

Joanne Gaudreau stopped the interview to ask for her cat, Chester. Simone, Joanne's attendant, smiled and brought Chester, the 20-pound ginger cat, from the bedroom. He sat on a high platform, at eye level with Joanne, and serenely watched the proceedings.

When she moved out of George Pearson Hospital in 2002, one of the things Joanne wanted most was a cat. Chester obliged.

For someone like Joanne, who had lived in Pearson for 34 years, the possibility of independent living was difficult for staff to accept—and in some ways for Joanne herself. "I was a little afraid," said Joanne, who has Cerebral Palsy (CP). She takes time to communicate verbally, but her meaning is clear. "I'd never lived on my own before, but it was my idea. I wanted to."

The discharge staff were surprised that she wanted to move out, Joanne remembered. Some felt she would be safer staying in hospital. Once her mind was made up, though, there was no stopping her.



Outside Hospital Walls

by Joanne Gaudreau

*There's a great big world out there
Watching the handicapped and waiting
For them to get out from behind
The walls that surround them.*

*Oh it would be a great adventure
Who can tell what lies ahead?
It might be fame and fortune
Or, it might be a blow to your pride
Or the world outside might be
Happy and gay*

*Whatever happens it's worth the effort.
Let's go and see what the world has to
Offer us.*

"Every week Joanne would grill me," said CARMA's Heather Morrison. "Have you found me a place yet?" It's clear, according to Heather, who made it happen. "It was Joanne who got Joanne out, it wasn't us. Her determination to keep at it literally for years was amazing. Now that she's out, she's not disappointed."

And it did take years. A lot of people helped, Joanne said. "Heather used to come and see me, talk to me. She talked to people at the team meetings."

Taz Pirbhai said, "We worked with the Pearson discharge team. We went to meetings, helped develop all the parts of Joanne's

discharge plan. We knew with the right combination of support and care hours, she would make it.”

“And I sat with Joanne, helped her envision the life she wanted, what qualities she wanted in an attendant, what she wanted to do with her time.”

From there, CARMA supported Joanne through the lengthy discharge process. Finally, fate intervened in a sad way: the death of one of Joanne’s mentors, Mary Williams. When Mary died, her apartment in St. George’s Place became available, and Joanne was accepted. It was a bittersweet day for Joanne who was saddened by the loss of her friend, but overjoyed to be moving out on her own.

“Mary used to be my roommate at Pearson and now I am in her apartment,” said Joanne. She adds with a gleam in her eye, “She still comes to visit me.” Once she moved in, Heather showed Joanne around the neighbourhood, and helped her buy groceries and other supplies to set up the apartment.

“CARMA is a wonderful organization,” Joanne said. “It’s a wonderful opportunity to be able to live on your own.”

As part of the discharge plan, Paul and Taz connected Joanne with Spectrum, a community living agency that now provides her attendants—and much more. “Every Friday I go there for lunch,” Joanne says.

“I’m really impressed with Spectrum,” said Heather. “They go way beyond providing attendants. They are committed to helping people really participate and have a good life. I don’t know any other agency that cares like they do.” Funding for Joanne’s care goes directly to Spectrum who provides and manages her attendants.

Joanne’s roommate Cynthia, another Spectrum employee, “is wonderful and helps me a lot,” Joanne said. Her two good friends, Barb and Veronica, also from Pearson, live in her building.

The new life Joanne has built for herself is full and she is ticking off goals faster than most people. She’s met her goal to have a cat—thanks to Heather. She has flown to Kelowna to see her 93-year-old mother. When asked how she liked flying, Joanne’s whole body reacts along with her smile. The goal that seemed to excite her the most is skiing. Her eyes shine and Simone nods having no doubt Joanne will do it.

Her less risk-taking activities include taking SkyTrain to Metrotown, swimming at Pearson and weekly visits to church. And she loves to write poetry.

“I still have friends at Pearson,” she said. “I go visit them on Saturdays.” And Joanne still calls Heather every morning to chat.

As a final note, when we sent this report to the presses, we heard that Joanne had indeed sit-skied down Seymour Mountain.



The new life Joanne has built for herself is full and she is ticking off goals faster than most.

Max Kamski

Having coffee with Max Kamski and his friends Ivona and Teresa, you realize you are in the company of lucky people. They have transcended all sorts of obstacles to form an uncommon connection with one another, of affection, humour and understanding. It's a testament to the power of relationship to transform people's lives.

For certain, Max himself is lucky. A man with Multiple Sclerosis (MS) who works hard to communicate verbally, he has a great friend and ally in Ivona. She was a driving force in his move out of George Pearson Centre into his own Burnaby apartment.

But it's clear from Ivona's teasing of Max and his smile, that she too is lucky. She is not only the anchor of Max's client support group, but she is also his friend. Teresa, Max's attendant, has also become a friend.

It was Ivona who first approached Max when he was living at Pearson. She was visiting another resident when she heard about Max who spoke Polish, her native tongue. She learned that, apart from his mother, Max didn't have too many people around him, so she went to say hello.

"When we met, he talked about a place he lived before in Port Moody," Ivona remembered. "I realized he had liked having his own place. And knowing him better now, I know he likes to be the boss."

Max said, "The idea of moving out was already in my head. But the staff said, 'you're lucky to be here.'" He felt they were encouraging him to stay. The nurses said, if he moved out, he would be back in a few months, but he was not deterred. "I have big physical problems, but I hope not mental. Nobody's perfect."

Adjusting Max's pillow, Ivona said, "Some people are OK at Pearson. I knew Max wasn't." She had met CARMA's Paul Gauthier, so she went to talk to him about what was involved in moving out of the centre. Max remembers how friendly the CARMA people were when they visited him to talk the idea over.

Paul said that, "Max's discharge had difficult and easy aspects. Easy because Max had a great support network—having someone like Ivona to help us. Hard because of his care needs."

But Ivona was also able to assist CARMA with a care plan. "She gave us a detailed 24-hour plan for Max," said Paul. "That was a great help to us because she knew him best. Then we were able to build the support plan to get his home care hours."



Max said, "The idea of moving out was already in my head. But the [Pearson] staff said, 'you're lucky to be here.'"

CARMA attended the discharge planning meetings at Pearson. Paul and Taz researched funding options, housing and various ministry resources. "We became a tight unit," said Paul. "Personally, it was one of the best projects I've ever worked on." Max also had a wonderful occupational therapist and physiotherapist at Pearson who helped him get "every gadget in the book."

Ivona sent "kazillions" of letters to housing coops. "When I came to see this place, I was glad," she said. "Many disability suites are on the main floor and dark. You can see all the light here and the big balcony."

Paul remembered that finding housing was hard. "But Ivona did most of the searching and once housing was in place, CARMA went after his long term care hours, equipment and everything else."

Securing the care hours Max needed was a long process. Max needs 24-hour care and, in the end, he did not receive the maximum possible hours, or even near that. "The good news," Paul said, "was that we found a great attendant, Teresa, who speaks Polish and who loves Max to death." Though the hours weren't what CARMA and Max had hoped for, they made them work. "The people were the key," according to Paul. "It's rare to find people who connect so well. This was a success story that exceeded, everyone's expectations."

Everything was set and Max was ready to move out. Max said that CARMA was "a big help setting up his apartment." CARMA volunteers took furnishings and household items from its store of donations and delivered them. Ivona also rounded up donations from the Polish community.

Max now has parties at his apartment. He tires in the evenings, but he loves having people in his home. "And my daughter didn't like to come to Pearson, but she comes here to see me," Max said.

CARMA is less involved in Max's day-to-day life now, but Max goes to some of their social functions and he knows they are there if he needs them. He is part of the Choices in Support for Independent Living program, with a five-person client support group. The group is responsible for Max's home support dollars, including recruiting and training attendants. With Ivona as the main member, Max's affairs are managed carefully guided by his wishes.

"It's rare to find people who connect so well. This was a success story that exceeded, everyone's expectations."



Max and Ivona

“In Max,” Paul said, “CARMA really has one of our greatest successes. Not only did we help him find his own place, but we were able to help connect him with the Polish community which was so important to him. It’s one of the stories that makes you feel really good.”

“When I was in Pearson,” Max said, “I was thinking about going outside. Now that I’m here, I want to stay inside.”

Conclusion

For us, CARMA is a big reality in a small package. Our activities and our projects are modest in scope, but the impact on the people we work with is life-changing. Our capacity building projects, for example, have created a crucible for the growth of personal satisfaction, and increased communication and bonds between people that did not exist before.

We continue to be inspired by people who find the courage to choose, to fundamentally change their lives when so many forces are seemingly stacked against them. In being there with them, and remaining attentive to what is needed, both within an individual's attitudes and within the institutions that affect them, all of us at CARMA continue to learn: about human strength and vulnerability, about the significance of the most simple connections among people, about how one person's success is worth so much to others, and about the inherent dignity of each person.

Earlier in this report, we said that the systemic barriers people in Pearson Centre face are essentially the same as all people with disabilities, though they differ in degree. For this reason, too, we see CARMA's work as a small but vital contribution to people with disabilities' inclusion and recognition as full participating citizens.

Appendix A

About the Vancouver Coastal Health's SMART Fund

The Sharon Martin Community Health Trust Fund was conceived in 1997 as a major tool for new investment in health improvements. The Fund supports innovative, cost-effective community based initiatives that promote and improve the health of residents in the Vancouver Coastal Health region.

All projects supported by the SMART Fund work to build capacity within their respective communities. This is accomplished through recognizing and enhancing the expertise and participation of their members, and involving the development of new partnerships, networks and contacts within and amongst communities. The SMART Fund's vision is "People in communities have equitable access to health resources, make healthy choices and work together to create community-based solutions to health issues."

The Fund is named in honour of the late Sharon Martin, the founding Director of Community and Public Involvement for the Vancouver/Richmond Health Board, one of the predecessors of Vancouver Coastal Health. Sharon was a passionate believer in nurturing healthy communities through community development and public involvement. The SMART Fund is a tribute to these beliefs.

Appendix B

BC Coalition of People with Disabilities

The BC Coalition of People with Disabilities (BCCPD) is a cross-disability umbrella group representing people with disabilities throughout BC. The organization's mandate is to raise public and political awareness around issues of concern to disability communities and to create change. Through its work, BCCPD hopes to improve people with disabilities' access to all aspects of community living.

To meet these goals, the BCCPD:

- advocates with all levels of government to improve policies and attitudes that affect people with disabilities
- promotes public awareness of disability issues through conferences, special projects and the media
- provides individual and group advocacy for people with disabilities
- serves on government panels and committees
- shares information and self-help skills with people with disabilities and disability organizations

In addition to **CARMA**, the program profiled in this report, BCCPD programs include:

- **Advocacy Access**, BCCPD's oldest program, which helps people with disabilities access income assistance benefits, CPP disability benefits and other disability-related programs and services.
- **The AIDS and Disability Action Program** offering HIV/AIDS prevention material in a variety of accessible formats. ADAP is now a core component of the **Wellness and Disability Initiative** which provides a range of health and wellness information in plain language and alternative formats. Services include a research and reference service, an in-house library and a web site.
- **The Individualized Funding and Autonomous Planning Project** has responsibilities for community outreach and development. Its mandate is to develop a community-supported strategy for future individualized funding services.
- **Transition** magazine, published six times a year, examines a broad range of issues of concern to people with disabilities, from the political to the personal.



**“Doing Whatever it Takes”: Profiles of Peer-Supported Transition
from a Care Facility to the Community**

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