

To date there hasn't been any sign of tension or teeth grinding. I attribute this to careful planning by a lot of people. The weekly lunch visits to the CLNG activity center helped a great deal. Every Thursday, Kathy Balcom, who is now his house supervisor, would pick the 4 men up and take them to the center, where they would get a chance to meet staff and other CLNG clients,

At the Final Transitional Planning and Discharge Meeting on July 4<sup>th</sup>, besides myself and my daughter, there were 8 people around the table who had a major role in Richard's successful move. Janice Rowe chaired the meeting. By a copy of this letter to her I request that she send a copy of this letter to them so they will know how happy I am with the outcome of this long process

I would also like to thank you for your understanding during the 10 months of construction delays that occurred with Ricky's new house. I think that keeping Ward W4C functioning on as near as normal basis as possible, during this period, did a lot to eliminate the trauma that might have occurred if the men had been moved to a temporary living area. The staff of W4C have now scattered. I think that Jackie Bryan would know who they are. If possible, I would appreciate them getting a copy of this letter as I appreciate so much the care they gave Ricky over the years.

I don't know what our family life would have been like without the loving and professional staff of the RRC. They gave Ricky the care and developed what potential he had better than we ever could have if he had stayed at home.

Ricky is starting a new phase in his life. His CLNG home is well staffed with experienced people. Marg Leaver, who has worked with him at the RRC, has joined CLNG as one of the "day caregivers" at his home. The dental and medical arrangements for him are satisfactory. The dental clinic at the Kemptville Hospital has experience with mentally handicapped patients. A local doctor has read his file and accepted him as a patient. A 'meet and greet' appointment has been made for this coming week so that he can meet Ricky before he has a medical problem.

I feel very lucky and grateful to a lot of people for the way things have worked out.

Yours very truly

Douglas R. Graham

Copies to:  
Wilma Prince RRC  
Janice Rowe MCSS

*Stories as featured on:*



[www.communitylivingontario.ca](http://www.communitylivingontario.ca)

## “Never be Frightened” about Community Living: Parent

Thursday, December 8, 2005 - Natalie Miller, Community Living Leaders

When her son was a small boy, Lorraine Lefaive feared for his safety.

One time, Ronald ran out of the yard through an unlocked gate and played in the sewer ditch. His mom found him covered in green muck.

Another time, he hit his sleeping twin brother with a tin garbage can.

When he turned on the gas stove in the middle of the night, Lorraine knew Ronald, who had no sense of danger, needed help.

“That’s when I knew he was going to harm himself,” the Windsor mother says.

At age six, Ronald, who can’t speak and has an intellectual disability as a result of being born without a thyroid gland, moved to Southwestern Regional Centre, a Blenheim institution for people who have intellectual disabilities.

“It was just to give us a rest,” says Lorraine. “They kept him there. They had a permanent position for him. At the time when (the twins) were born...they were really in bad shape.”

Over the years, Lorraine visited Ronald there, although it was too hard on her husband, she says. “We did go and see him. The place did very well with the children. Ronald had the best of care up there.”

He lived there for more than 40 years.

About a month ago, Ronald, 43, and two of his co-residents at Southwestern moved into a group home in Essex. Lorraine, while initially petrified about her son’s safety, says he is adjusting well and she is confident her son is in a good place.

“At first, I was very, very frightened,” says Lorraine.

“He doesn’t know any danger.”

As the government prepares to close the remaining three large institutions for people with intellectual disabilities, about 1,000 will move into community. It’s part of the Province’s push to offer community-based supports to people instead of institutional-based care.

The process to transition Ronald from Southwestern to the community took about three months. Lorraine says she worried herself sick but received support through the process. After attending many meetings and touring possible residences, she felt better. “Nothing’s done overnight,” she says. “I would like to tell (other family members) to never be frightened.”

Ronald and his roommates have 24-hour support seven days a week through Community Living Essex County in their new residence. Lorraine likes the fact her son receives more individualized support now and something as simple as the smell of homemade cooking is one of his new experiences. “I couldn’t get over how quiet and happy he looked.”

## Joanne - The Right Choice

Tuesday, October 7, 2003 - Community Living Ontario

Joanne's parents say they will always be grateful for the care their daughter received during the 13 years she lived at the Southwestern Regional Centre (SRC). But the Johns also know that when they ask Joanne if she would like to go back, she shakes her head.

Prior to living in SRC, Joanne spent three years at the Rideau Centre in Smiths Falls. That was a very difficult time, as her parents could only travel the very long distance to see her once every three months. They knew Joanne was unhappy because she didn't eat.

Joanne is one of nine children born to Joe and Evelyn. Each of her siblings has achieved a university degree and has made their parents proud. But it is Joanne's challenges that have shaped the lives of the Johns family.

In 1946, Joe and Evelyn became founding parents of the Cerebral Palsy Association which eventually expanded to become the Chatham Children's Treatment Centre and is now the Prism Centre. They also became involved when the Ontario government announced plans to close institutions that housed people with intellectual disabilities. Joe led a group that rallied support from families who wanted to keep them open. Today, while Joe still expresses concerns about whether community living is the answer for all people with intellectual disabilities, he readily admits that Joanne is happier and healthier living in the group home that she shares with four others.

When they finally decided that a move back to the community was the right choice for Joanne, the Johns say that the government was very helpful. "They did a great job in making the move go smoothly," says Joe.

Joanne, who is 57 years old, may be non-verbal but she is a very emotional person, says her mother. Even something such as beautiful Christmas music can make her cry. "It's hard sometimes, not knowing exactly what she is thinking." Evelyn says her daughter is calmer since she moved to the group home. "I think she's definitely happier there being closer to us. To think -- we fought it for so long."

# Mom Refuses to Deny Son Right to Community Life

## Willing to Speak with Other Families Considering Move Away from Institutions

Friday, January 26, 2007 - Natalie Miller, Community Living Leaders

On her third trip from hospital back to her son's home following his Grand Mal seizure, a support worker offered the distraught mother a much-needed embrace.

The memory remains poignant for Toronto senior Molly Croke, whose son, Bill, 42, has varied special needs.

"The staff at that group home are part of the extended family," says Molly, 66.

"They care deeply about Bill and they care about me too. We're all part of a support system."

That support system enables Bill to live in a regular house in a regular Toronto neighbourhood. It's a much different, more fulfilling experience than Bill had earlier in his life, says Molly.

Born with an intellectual disability, Bill was later diagnosed with autism. He also has epilepsy and episodes of multiple Grand Mal seizures.

At age six, Molly and her husband placed Bill in Huronia Regional Centre in Orillia, an institution for people who have intellectual disabilities. Molly says in addition to Bill's medical conditions, "he was extremely hyperactive. On the average day, he was on the go at least 20 hours out of every 24 and we found it impossible to care for him at home."

They visited Bill weekly. "He never resisted going back to (Huronian)," says Molly. "That was one of the factors we used to assess if he was happy there. Being non-verbal, you have to pick up on (other hints from Bill)."

During the time Bill lived at Huronia, his parents were active members of Community Living Toronto (then called the Metro Toronto Association for the Mentally Retarded). "In the early 1980s, we learned of a project to care for the multiply handicapped in the community. This was the beginning of deinstitutionalization of developmentally handicapped individuals in Toronto."

"I was very fearful," Molly recalls. "I can totally understand what (other) parents are feeling."

The Liberal government announced in 2004 it would close Huronia, Rideau Regional Centre in Smiths Falls and Southwestern Regional Centre in Blenheim by March 31, 2009 in a move towards a system of community-based supports for people with intellectual disabilities. Since the announcement, some of the remaining 1,000 or so people have moved into the community.

When Bill moved out of Huronia, "everything was not roses," says Molly. "My biggest concern was his family physician really didn't understand a lot about developmental handicaps and made inappropriate decisions about Bill's medication." Her son wound up at the Whitby Mental Health Centre. It was a difficult time.

However, the family found another physician who was better suited to meet Bill's needs. "Things have been so much better," she says. "We did have to work through some difficulties but on the whole it has been a very positive experience."

For the past 15 years Bill has lived in the same home with two other people who have special needs and is supported by staff from Community Living Toronto.

"There's a lot of richness to the experiences he has," says Molly, noting her son delivers Meals on Wheels once a week and participates in activities including swimming and horseback riding.

"I'm certainly no fountain of wisdom. All I can do is share my experience. I really have no regrets at this point."

Molly recalls the bottom line that helped her come to the decision for Bill to move out of the institution.

"I had to ask myself if I had the right to deny Bill of the richness he would receive in the community. The answer had to be 'no' I did not have that right."

Molly says she is willing to speak to other parents who may have questions or concerns about deinstitutionalization. Her telephone number is available through Community Living Toronto.

## Four Men Make 'Seamless' Transition to Community Home

Thursday, January 25, 2007 - Michelle Strutzenberger, Community Living Leaders

Four men from Rideau Regional Centre in Smiths Falls made a “seamless” transition to a community home last year where they now live safe, comfortable and purposeful lives, according to family-members.

“My god, it’s just a blessing,” says Lucien Alarie, parent of one of the men, Claude Alarie. Parents and family-members of the other three men are also very pleased with the new housing arrangement.

But when they first learned that Rideau would be closing its doors, none of these same family-members was very positive about the change.

“They were adamantly opposed to community placement,” Debra Black, manager of residential services at Community Living North Grenville remembers.

Doug Graham, another parent, says his son, Richard, had been living at Rideau for 46 years. Richard, now 57, had been moved there at the age of 11 and it had been essentially all the life he had ever known.

“I was quite concerned,” says Graham, when he first learned that he would have to look into alternative living arrangements.

Alarie admits to the same feelings. “[Rideau] was his home,” he says of his son, Claude. “He had been used to that place for 50 years.”

Both parents say they had found the living quarters, staff and activities at Rideau more than adequate for their children.

It was as they began searching out the community options, however, that they began to see an alternative that just might work.

For Graham, the process of changing his perception began when Rideau staff mentioned to him that there were four men from the institution who would do well as house-mates.

“They told me there were four men who had the same quiet disposition as my son and would make a good team,” Graham remembers.

Privacy laws prohibited him from contacting the family-members of these men, but staff arranged for the families to connect with Graham if they were interested in looking at a community placement together.

All three families contacted Graham and there began the transition for the four men, Claude, Richard, George, and Henryk, out of Rideau and into their – literally -- brand-new home in the community.

Graham says the transition was so successful due to “lot of cooperation between Rideau staff, Community Living North Grenville, and the parents.”

When the families of the four met, they agreed that they wanted to look into community options together. After doing some research, they decided to look into placements in Kemptville, which is about 40 minutes from Ottawa.

Graham says the smaller agency and warmth of the staff appealed to the families. "We decided they were the ones we wanted to look after our sons."

Alarie says it was meeting the board and staff at Community Living North Grenville that changed his mind.

"It took away most of the worries we had," he says. "It just gave us an awful lot of confidence."

The meeting with the board resulted in a decision to build a new home for the four men, as approved by the Ministry of Community and Social Services.

Construction on the house was started in the spring, 2005, in a large, quiet subdivision in Kemptville. The families were involved in the whole planning process, and their suggestions were taken into account for the new home. For zoning reasons, the house wasn't completed until the following year.

However, Debra Black, manager of residential services at Community Living North Grenville, says this worked out for the best. "To me, at the end of the day, that extra time contributed to the success," she says.

Every week throughout that year, staff from the community living association, brought the men from Rideau to the association for a variety of activities. They then took them by the house and explained that in time it would be their new home. The men had a chance to get used to their new town and new agency and to see their new home in progress. Alarie agrees the extra time gave his son, Claude, time to familiarize himself with the new setting. "When it was time to move, he wanted to go. He knew it was his new home."

On moving day, Alarie and his wife Yolande, arrived a little after the men did. They found their son helping the movers take stuff into the house. "He had this big smile," Alarie remembers. "He looked happy." That, says Alarie, took away any remaining fears.

Today the lives of the men at the home are safe, comfortable and purposeful, according to family-members. The home is large with a fenced-in backyard, a sprinkler system and an emergency system for heating and lights. The street on which it is situated is quiet with little traffic and well-spaced homes.

Claude has a small job at a nearby long-term care home. Staff-members are working at helping Richard to communicate more using alternate methods.

Alarie notes that the setting is more conducive to "family-life." At birthdays, he and his wife bring in a cake. At Christmas, they decorated a tree with the men.

Both Graham and Alarie point out those staff-members go above and beyond to meet individual needs and make life enjoyable.

"The four families are happy and without fear now," says Alarie, noting that all of the parents are senior citizens. "In our minds and hearts, we know our children are totally protected by that organization in Kemptville."



## An HRC Resident Finds 'Home' in the Community

Thursday, December 14, 2006 - Michelle Strutzenberger, Community Living Leaders

On any day at the group home where Bill lives, one may come through the front door and smell dinner cooking in the oven, hear the laundry spinning in the dryer, see the little knickknacks hanging on the walls. They are small things that many people take for granted.

But for Bill, and for Joan Tonner, his sister, they are important. They are little daily reminders that Bill has come home.

For over 45 years, Bill resided at Huronia Regional Centre (HRC) in Orillia. His family moved him there in 1953, when he was five years old. "The deal was that he would be there forever," says Joan. She and the rest of her family found a great deal of comfort and security in the institutional paradigm, knowing that Bill was well-looked-after and that it was a government-funded facility.

But as it became increasingly clear that the centre would be closing sometime down the road, the family became convinced that they needed to move Bill into the community. "We saw even then the range of services beginning to shrink there," says Joan, adding that this was a driving factor in the family's decision to look at other options.

But while they agreed it was important to do this, Joan, who had taken on the role of advocate for her brother, says she was definitely not keen about the decision. She was afraid for Bill. Would he receive the level of care he requires in the community?

Along with an intellectual disability, Bill has mobility limitations. He does not communicate verbally, although he can get his messages across in other ways, through sounds, facial expressions and gestures. Over the last few years, his medical needs have increased significantly and he now requires a catheter and G-tube for feeding.

"Bill has always been a 'complex-care' guy," says Joan. He requires 24-hour care and monitoring.

Her concerns about 'care' match those of families who still have family-members living at HRC.

Joan says that in the experience of herself and Bill, while it has required some networking, they have managed to connect with a team of doctors, visiting nurses, physiotherapists and specialists in the community who care for all of Bill's medical needs. "It has worked for us," she says.

In an article about Bill published in Orillia Today, June 10, 2005, "The long journey out of HRC," Paul Doig, Ministry of Community and Social Services spokesman, pointed out that Ontario communities offer an range of options for people with intellectual disabilities, as the province has had almost 30 years of experience supporting people as they move out of institutions. "More than 370 agencies provide a wide range of services to more than 39,000 individuals with a variety of needs," said Doig. "Already living in the community [are] individuals with needs every bit as complex as residents in the three remaining provincially-operated facilities." Bill is one of those individuals.

The medical care is there for him, accessed like any other community-member would access it. The medical team does not come to Bill. He must go to his appointments. Sometimes he must wait for those appointments. But it can also be seen this way: it is another indication of the status Bill has acquired – he is a community-member.

And that is huge, says Joan.

“His connection with the community now parallels what yours and mine would be,” she says. “He goes to the community doctor and dentist. When we go out for walks, we go in his neighbourhood.”

Bill still continues to draw on specialized services as he attends a daily adult program. “But it’s like us going to work or school,” Joan points out. “He has a variety of environments that he interacts with. And I think that’s healthy.”

Needless to say, while Joan may have been reluctant about moving her brother from HRC, she and her family do not regret the move. “For us it’s been a ‘wow,’ why didn’t we do this sooner?” she says.

It was as she explored the various community-based options over a period of eight months that Joan’s whole perspective was transformed. “I saw something so much better,” she says. “After that, there was no looking back.”

It’s difficult for her to adequately express the nuances of Bill’s new reality. She stresses that at HRC her brother was well-cared-for, the family was connected and involved with him and that staff was professional. But despite all the best efforts of everyone involved, one couldn’t get away from the fact that the institution was “a big machine and a big bureaucracy.”

The switch to the specialized care group home in Barrie, run by Simcoe Community Services, has just enhanced Bill’s overall quality of life, she says. He is not only well-cared-for. He is thriving. The smaller living unit, the smaller number of co-residents, and the interaction with a defined number of staff day-to-day contributes to the home-like setting.

Bill experiences all the day-to-day comings and goings of a home such as taking trips in the van, watching dinner being prepared, hearing the laundry washing.

“He also gets a lot of personal care and attention, just by being there in the cluster function of the home,” she says. Staff-members work conscientiously to get close to Bill, to know his preferences and meet his individual needs.

Bill cannot communicate verbally, as mentioned, but through his non-verbal means, through his actions and gestures, Joan has noticed that he is evolving into a more positive and confident person. Joan has noticed times that he will stand beside a staff-member and place a hand on his/her shoulder. “This is a guy who didn’t want to be touched, who didn’t want to get close to people... That he does this now is an indication of the trust, comfort, safety that he feels.”

In the safety and peace of the home, Bill has taken to exploring things, looking at things, touching things. He even plays games now

“It’s amazing. These are unbelievable things,” says Joan. “They just didn’t use to happen.”

Joan is someone who understands the fears and frustrations of a family-member of a resident at HRC. She has felt that same sense of security that families feel in depending on a government-run institution. But she points out that government dollars fund the community-based agencies which support people with intellectual disabilities. “It’s

not that the government is turning its back on supporting people with disabilities," she says. "They've just found a more humane, community-based, effective way to do it."

In a letter to the Toronto Star recently, Keith Powell, executive director of Community Living Ontario noted that in addition to the individualized funding that comes with each person that leaves the institutions, the Ministry has provided \$110 million additional dollars to ensure that necessary community services and supports will exist for the people leaving these facilities. "Community Living Ontario will hold the Ministry to these commitments," he said.

"My experience is that exploring community-based alternatives for care has yielded significant benefits for Bill's quality of life," says Joan. "I would encourage others to explore as well. I think they will find rich opportunities that can meet and exceed the services and quality of life provided in the institution."



Community Living  
Ontario

Intégration communautaire  
Ontario

240 Duncan Mill Road, Suite 403  
Toronto, Ontario M3B 3S6  
Tel: 416-447-4348  
Fax: 416-447-8974  
Toll Free: 1-800-278-8025

[www.communitylivingontario.ca](http://www.communitylivingontario.ca)