



A Decision That Needs Rethinking

By Rose Flaig, President, Community Living-Manitoba

You would never build another orphanage for children. It's an outdated model of service. We've found other ways to support children.

You would never consider building Residential Schools again for First Nations People. It's an outdated model of service and we've found other ways to respond to needs.

So why in 2005 would the Manitoba Government be contemplating a \$40 million rebuild of the Manitoba Developmental Centre (MDC) in Portage La Prairie to support 402 people who happen to live with intellectual disabilities?

It's a extremely outdated approach and we have found other ways to support people to live in their community. It is a total anachronism.

Manitoba has demonstrated creativity and can be proud of how we have developed new options in the community for people living with an intellectual disability. Models of support range from four people living together, two or three people sharing a house, living in apartment blocks, supporting people in their family home, foster homes, co-ops, and just plain living on your own. With such gains in innovative ways of supporting people, why would we consider stepping back in time to a model that prevents real diversity in community development?

The story is about planning for community participation. It was about choices in everyday life decisions and the beginning of making choices about shopping, banking, work, when to get up and go to bed. It is about relationships, recreation, feeling sad and happy. It is about experiencing the community at its best and worst.

Despite the modest gains demonstrated during the 1980s and 1990s, thousands of people with intellectual disabilities across Canada remain trapped in institutional environments. They are there not by choice—they are there because our efforts



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Protesters at the February 18, 2005, rally at the Leg

Norm McLeod, parent and member of the National Task Force on Deinstitutionalization, gave the following address at a rally held February 18, 2005, in front of the Manitoba Legislature.

I came here today, just as people from across Manitoba and across Canada have come, to **voice outrage** at what the Gary Doer Government has announced. This government has a plan that **violates the fundamental human rights of people in this province**. Our brothers and sisters, our sons and daughters are **losing their rights and freedoms** to participate as **free members of our society**.

This government is proud of itself, it is proud to be spending 40 million dollars to rebuild an institution that continues to remove people from society. The rest of Canada, the rest of the western world has know for at least 40 years that all people **live better, happier and more fulfilling** lives when they live in the community.

Why does Gary Doer believe our sons and daughter our sisters and brothers should

be shunned away in the dark corners of institution? This is one of the **most ill conceived ideas** this or any government has had, **and we know it**.

I am here to tell you that the Canadian Association for Community Living and the People First Task Force on Deinstitutionalization and our thousands of members all across Canada **stand beside you in fighting this government's decision**.

This decision is out of sync with what's happening across Canada. British Columbia and Newfoundland have both closed their institutions. Ontario last year made a commitment to close its remaining institutions within the next three years. Other provinces are committed to support people to live in the community.

This government's decision is a **threat. It's a threat to families who have young children with disabilities**. Instead of providing services in the community, this government in the future will want your children to move into the institution away from your family and friends. No institution will ever replace the love and care of a family. This \$40 million should be used to support people in their community, not on rebuilding a relic of the past.

It is a threat to the people currently living in the institution. They will never have the opportunity to live as valued citizens of our community. Instead, they will continue to be locked away.

It is a threat to people that have a disability and live and work in our community. It would be easy for this government to say we don't have any money to provide services in the

Shame on You

community, and you have to go into an institution.

It's a threat to society. Institutions prevent citizens from adding value and diversity to our community. Institutions do not respect the different and unique gifts that we all have. Institutions deny us an opportunity to show compassion, love, respect, and support for each other. Institutions tell our community that some of us are not valued members of our society.

Being sent to an institution is worse than going to prison—at least in prison you get released at the end of your sentence. Institutionalization is a sentence for life. And what's the crime? It makes no sense, it isn't right, we know better than this. Why isn't this government listening to the people most impacted by its decision?

Shame on You

Shame-on-you for not believing that people with disabilities are part of the fabric that makes communities strong and diverse.

Shame-on-you for not believing that individuals with disabilities should be entitled to live in the community with their families and friends.

Shame-on-you for not believing that all individuals whether they have a disability or not have something to wonderful to contribute.

Shame-on-you for not listening to the people here today.

Shame-on-you for not consulting with organizations such as Community Living - Manitoba and People First.

Shame-on-you for not understanding that diversity of your citizens build strong and vibrant communities

I call on Premier Gary Doer and Minister Melnick to immediately stop your plans to rebuild your institution at Portage la Prairie.

It takes courage to admit a mistake. Now is the time to show leadership and courage.

I ask the Minister and the Premier to actively and meaningful engage Community Living - Manitoba and People First **to dream a bigger \$40 million idea**.

To support people and help them find their **rightful** place in society as our neighbours and friends. To dream a \$40 million vision that does not include removing people, shunning people away from society in hidden dark corners of an institution.

I ask this government to do what is **right** not just for people with a disability **but for all of society**.

I challenge this government to **lead with vision, compassion and justice for all its citizens**.

Life is Good in the Community

Corey's cozy two-bedroom apartment is filled with mementos of special events and pictures of special people.

"My life is a lot different now... it's a lot better. Now I have choices," he says.

Corey is comparing his life now to the life he knew while living as a resident at Portage la Prairie's Manitoba Developmental Centre (MDC). Corey spent several years of his life there before having the opportunity to live in the community as a participant of the program "In the Company of Friends." To make his point, Corey describes a typical day in his life in the institution.

"When I lived at MDC, I shared a room with two other residents. I got up in the morning at 7:00. I got bathed and dressed, and then I went and had breakfast with all the other residents. We usually had a choice of two things to eat. After breakfast I went to work. At lunchtime I had whatever was being served with the other residents and then went back to work until 3:30. When I finished work I went back to my room until dinnertime, where I ate whatever was being served. Sometimes I'd go to the lounge and watch TV but there were usually 16 to 18 of us so I almost never got to watch what I wanted. Sometimes in the evening I'd go to the canteen and visit. Bedtime was usually 9:30 or 10."

He goes on to contrast this with his life today, living in the community.

"Now when I get up in the morning, I decide what I'm going to have for breakfast... and I can have anything I want. I usually go to work till lunchtime then again after lunch. When I'm done work, sometimes I go home and relax. I might watch TV or I might listen to CDs. Sometimes I go out for coffee with friends. That's a lot different from when I was at MDC where I got to go out for coffee once in a blue moon and only if someone invited me out. I could never go just because I wanted to or because it was my idea! Now I get to choose what I want to have for dinner and I help to make it. I get to decide if I want to invite someone over to my place for supper. And when I'm done supper, if I want to call my family or friends, I just do. When I lived at MDC, I could only call my uncles once a month or they could call me at a set time, but my calls were always monitored. Now I get to call anyone I want, whenever I want and no one listens to my calls."

Corey lives independently with the assistance of his friends and family as well as caregivers. He says he's happier than he's ever been in his life because of the choices he gets to make and the control he has over his own life.

"Now I have my own place that I am proud of. I sign my own cheques. I pick my own staff. I get to pick out my own clothes and glasses. Before, someone always did those things for

me. Now I get to make crafts and give gifts to people I like. I couldn't give people gifts before, it wasn't allowed. Now I even have a girlfriend! I usually get to see her once a month."

Corey's life has changed in a number of other ways as well. When he resided in an institution, he usually missed out on family gatherings unless they were arranged far in advance. As a result, he was distanced further from his family. Now he regularly sees family members for weekends and on special occasions, and has particularly come to appreciate his new life recently after losing two elderly great-aunts.

"When I lived at MDC, I could only go to funerals for parents or brothers or sisters. I could never have gone to my aunts' funerals because they weren't a close enough relative, but that's not right because they're very important people to me. I'm really, really going to miss them."

"My life is a lot different now... it's a lot better. Now I have choices."

Corey's independence is also giving him an opportunity to dream like he's never been able to before.

"I never went on trips before. Since I've been living on my own, I've gone to visit family out west. I'm even planning a

trip to Chicago next summer to go to the Gentle Teaching Conference there."

Corey is particularly proud of the fact that two years ago he had the opportunity to meet Dr. John McGee, the founder of Gentle Teaching. More exciting to Corey is that he was later invited by Dr. McGee to be a co-teacher with him at a training session in Winnipeg last year.

"No one has ever asked me to teach other people things before. Dr. McGee said I did a great job!" says Corey.

Corey's family and friends get together with him annually to help plan what the next year might look like for him by completing a PATH (Planning Alternative Tomorrows with Hope). This encourages Corey to continue to dream of doing new and exciting things beyond what he's already accomplished.

"Some day, I'm even going to go to Hawaii!"

One of the biggest differences Corey cites is the quantity and the quality of the relationships he now has in his life. He has a circle of friends that he spends time with and does things with. He has a support network of people who he trusts to help him make important decisions. He also has staff that he had a say in hiring, so they are people with whom he feels safe and comfortable.

"Now when I get frustrated, the people in my life take time and talk me through it until I feel better. They help me to understand why things are the way they are. One time at MDC I got so frustrated because I couldn't do something I wanted and eight guys put me into lock-up. I was left there for several hours so I could 'think about it.' I didn't want to sit there and think about it. I wanted someone to help me!"

Today, Corey's biggest sorrow is that many of his friends still live at MDC. Corey's job through his day program allows him to see them on a regular basis as he delivers mail there but it's not the same as it would be if they were also living in the community. He thinks about them often and does what he can for them, particularly a former roommate.

"My friend can't come to my place so I get my staff to take me to see him. Sometimes we visit at the canteen and have a 'near beer' together. Sometimes I take pizza so we can have supper together. I wish he could come and live with me, but they say he can't. I don't think it's fair."

Corey's life is far from easy. He struggles with some things, just as the rest of us do, and he struggles with the ghosts of his past. Still, Corey loves his life.

"I get to make choices. I get to do what I want and see who I want. Those are really important things. Most important, I have people who care about me and who help me. I wouldn't want to go back to living at the MDC no matter what!"



Corey with his friend Linda

One is Too Many – Stepping into Freedom

We wear these ribbons to let Canadians know that too many people are still locked in institutions.

We are horrified that Canadians keep institutions open. We are angry that new kinds of institutions are being built.

The **black ribbon** is because people in institutions are not safe. Many have died. We mourn their deaths.



The **yellow ribbon** is for liberation—we want all people in institutions to step into freedom.

All people regardless of the severity of their disabilities should live in the community the support they need.

– A campaign of People First groups across Canada

Research Supports Community Living Preference

Heather Milton is a Masters student in the Faculty of Social Work at the University of Manitoba and is completing her thesis on community living versus institutions. In this article, she attempts to address the reasons given by the provincial government to continue to institutionalize people rather than include them in our communities.

The premise of the government is that deinstitutionalization is disruptive to the individuals, their families, and to service systems, and that the serious medical concerns of many of the individuals could not be adequately managed in the community.

To start, there has been considerable research done on family reactions to institutional closure. One of the studies involved following family reaction to the closure of an institution in Illinois in 1983. Initially, 81% of the families opposed the move and many of the families joined together to pursue a lawsuit that delayed the closure for months (Heller, Bond & Braddock, 1988).

The families did not believe their relatives would benefit from the increased normalization offered by community living and were concerned about the effect that separation from familiar staff and other residents, and the loss of regular routines would have on them. Their main concern was that the high level of medical care offered in the institution would not be provided in the community. However, the families reversed their attitudes in the months following the closure of the institution. The majority of the families were pleased with the improved quality of life of their relatives.

This research is supported by other research that had the same results—the families' attitudes usually changed from being opposed to closure to being pleased with the outcome of the relocation into the community (Kim, Larsen & Lakin, 2001).

This research also includes several helpful recommendations on how to

ease the stress of transfer out of institutions. Concern about family reaction therefore cannot be used as justification to perpetuate a poor quality of life for institutionalized individuals.

The concept of quality of life has been the focus of attention and debate over the past three decades. There is now general agreement that institutional care provides a poor quality of life as it maintains dependency, reduces choice, offers little opportunity for skill development, etc. Research supports the drive for community living because it demonstrates that increasing normalization is strongly linked to improving quality of life.

There is consensus that quality of life assessment of individuals with physical, mental or cognitive disabilities must be

The preference is always for normalization, community integration and community inclusion.

assessed in the same way as it would be for individuals in the general population, and that the individual's

point of view is the most important consideration.

Research clearly demonstrates that individuals with disabilities preference has always been for increased normalization. They prefer life in a large group home or foster home to life in an institution, prefer life in a small group home to life in a large group home, and prefer life in supported independent living to life in a small group home.

The preference is always for normalization, community integration and community inclusion.

While some individuals in MDC cannot live completely independently in the community, the decision to not meet their next preference—support life in the community—would contradict the body of research that clearly demonstrates this preference.

The huge amount of money that the provincial government proposes to spend refurbishing and upgrading a symbol of past injustice to thousands of individuals would be much better used to give them all the support they need to relocate and to live in community settings.

Finding peace at last

David Weremy is a busy man. Between his increasing involvement with People First of Winnipeg, his participation in barbeques and dinners as an

David is known as a caring and sensitive person, who has, at last, found a level of contentment. It has been a long road to find that peace. For many years, he would

not talk about his formative years spent in an institution.

"It's really only been since this funding issue came up with the \$40 million expansion at MDC that he's a lot more comfortable talking about his



David enjoying a cup of coffee with friends at the Jolly Mug

active member of the NDP party, and spending time on activities with friends and family, David enjoys a full and fulfilling life.

Now in his early 60s, he lives independently in his own apartment. Support workers visit for a few hours daily for companionship and to assist with grocery shopping, cooking and cleaning.

time there and the things that happened to him there and how it was when he left," says Melinda, one of David's support workers. "And it's only the last few years that he's been content and secure in his surroundings, and knows he has choices. He knows he can be independent and we're not going to take that away, no one's going to send him back to an institution."

In his own words . . .

My name is David Weremy and I lived at MDC for 18 years. It was a bad place to live. I was often hungry and did not feel safe. I was yelled at and kicked if I talked back to the staff. The staff never said anything when people were being mean to me. If you did something wrong, you were put in lock-up with nothing on and had to sleep on the bare floor. When I went to visit my mom, the staff told me not to say anything about what was going on. I ran away nine times because I never liked it there.

I came to Winnipeg and lived with my mom. My mom was sick so they were going to send me back to Portage. I told them if they sent me back I'd run away again. My social worker said she'd look after me, I told her I didn't want to live with too many boys.

She said she had a place—it didn't take her long—and then I went to visit the new place and I moved. It was OK at first but then no one wanted to do anything. We lived in a house and no one wanted to cut the lawn or shovel snow.

Then two girls were moving out of a suite and we decided to go there. That was a big move in one day! Then we fought too much after a while and the director said that somebody had to go. It took a while and then we found my suite.

Now my life is good! I live alone in an apartment. I have staff that helps me with cooking and laundry and with money. I have more freedom and nobody pushes me around. I can go out anywhere I want and nobody stops me. I had a bad life when I lived in Portage. It took a while but now I have a good life.

I don't know if people like it in the Manitoba Developmental Centre in Portage. We need to take them and show them what it's like uptown and other places. It was hard for me, it took a while, but it worked out in the end!

Living life to the fullest

Michael's life in the community is ordinary. He lives in a house in a nice residential area. He does all the regular things that people do—he goes to work every day, watches TV, plays guitar, goes out with friends for coffee, shops for groceries, does his banking. To everyone else, this is pretty unremarkable. For Michael, it is remarkable because he had previously been denied the opportunity to live an ordinary life.

He shares his home with two other men and loves to spend quiet time in his room, which was newly furnished when he moved in and freshly painted in colours that he chose. He has a radio and television, plus his own bathroom where he enjoys long, hot baths.

One of the many adjustments Michael had to make after moving into the community was having open access to the kitchen and being able to help himself to food. This, plus having seconds, was a welcome novelty, resulted in a few extra pounds but he is finding a new balance. He's quick to do his part in household duties and loves to help with his laundry. In the fall, raking the leaves in the backyard is Michael's favourite activity. So much so that staff almost have to drag him inside at dusk!

Best of all for Michael though, as such a sociable fellow, are all the opportunities to go out in the community. Whether it's coffee at a restaurant, visits to friends' houses, dances, supper outings, bowling, trips to the lake, hockey games, or visits with his family members, Michael is up for it. He is also just as happy to receive company and has others over to his house for coffee. And just like everyone likes to do during the Christmas season, a party at the house was a heartwarming evening spent with family and friends.

The hours are never empty, as Michael is able to fill his life and others with music. A devoted musician, he knows the words to numerous songs and loves to play his guitar at every opportunity. The recent replacement of his old and warped guitar with a brand new one was a real thrill and if possible, increased his joy in playing even more.

During the weekday, Michael takes pleasure in his job at the local Association for Community Living's Resource Centre. He started going to the Centre almost immediately after moving into the community. A conscientious worker, Michael works in the

recycling area pulling out staples and moving papers and boxes. In fact, he's so dedicated to his job that staff often has to force him to take breaks. Michael has his own bank account and visits the bank weekly to cash cheques and make deposits. He uses his income to purchase toiletries and personal items.

"I don't think Michael's quality of life can even compare to life in an institution," says Gail, the residential co-ordinator. "He seems happy and more at peace with himself. He has endless opportunities before him."

His move from an institution into the community, however, amply demonstrated how crucial planning is for this transition. In Michael's case, support workers now believe they could have done it better. In hindsight, they would have had a transition period during which familiar staff would have been there for the first couple of days as familiar faces to help Michael adjust to his new surroundings and answer any questions he might have.

"We fumbled through it but I'm sure Michael would have benefited from extra support. It was a very dramatic change. We found out that he can get very agitated if he loses something or perceives it to be stolen. It took some time

for us to learn but over time things have worked out," says Gail.

Michael's acceptance into the community has been two-way. Perhaps it is his friendly nature, with his tendency to immediately stick out his hand to shake the other person's hand, but Michael has been well received by other community members. People at the places he visits are quick to say "Hi, Michael."

Eager to participate in pretty much every activity, Michael also has lots of pats, hugs, handshakes, and kisses for everyone. Support workers note how polite he is and how much he appreciates and is grateful for everything.

The biggest concern for Michael now is his health, due to a positive test for TB many years ago. Staff is concerned that he tries to do too much but say it is hard to get him to slow down. Perhaps he is just trying to fit in as much life as possible to make up for the years he missed in the community.

(Names have been changed to protect privacy.)

A new take on life

It's a common phrase that we all utter at some point in our lives, *If I knew then, what I know now...* For some parents, it's a heartbreaking knowledge that could have changed their son or daughter's life.

Wade spent 13 years in an institution, from age 9 to 21. His mother Gwen always believed her son would live in the community again. Her eyes light up whenever she talks about him and the great life he now has living in an upscale neighbourhood with three women who are his friends and supporters.

People who have known Wade over his lifetime cannot believe how far he has come. The descriptions used by his caregivers at the institution include "psychotic" and "dangerous." During his time there, Wade was on heavy medication that kept him sedated. He wore diapers and always had two staff members with him on any outings.

Meanwhile, his mother Gwen ran the Manitoba Marathon every year hoping that the money she helped raise would buy Wade a home in the community. She became active with Arcane Horizon Inc., a support agency started by parents who shared the same desire to have their sons and daughters with challenging behaviours supported in a community setting.

This was a role that Gwen had to grow into. There was a time in her life that she did not have the strength or time to be an advocate. Without judging any other parents for the choices they make, she has many personal regrets over the decision to place Wade in an institution.

"It was only supposed to be a window of time before he was to be placed in a group home. But he was a square peg in a round hole," she says. "It was a very difficult decision and one I will always regret."

With a great deal of encouragement from Gwen, Arcane agreed to support Wade and after some searching the perfect staff person was found. Allison is a Gentle Teacher by nature and the two of them hit it off instantly and her role soon changed from staff to roommate. Allison and Wade now share a large home that she purchased with his needs in mind.

His days are spent delivering staff cheques, taking his journal to the Arcane office every day and helping with photocopying. He is able to communicate with people who know him and loves to hang out with them. One of his favourite activities is holidaying at the lake with his mom, where he loves to use the paddle boat and be outdoors.



Wade and his mom Gwen enjoy paddling in the water at the lake

Gwen had a great network that supported her quest for Wade to live in the community. Wade's father Don was a great support and loving participant. Friends were there whenever she got discouraged or ran into difficulties. Janice, Val and Michelle, three teachers who believe in the concept of community, supported Gwen in her journey to create a true community for Wade. Now they need only to see Wade at peace with the world, obviously safe and loved, to feel satisfied with that journey.

Gwen's greatest joy in seeing Wade living in the community is that peacefulness.



A summer birthday celebration with Wade, Gwen and Carlos, a former support worker who chooses

“He’s happier and he’s at peace. He has relationships,” she says. “And because he’s happier there’s less aggression, almost nonexistent. He feels like he belongs, which he does. And he’s accomplished a lot. That’s just by having positive relationships and people never giving up on him.”

One of the lessons learned in Wade’s transition from leaving an institution to go into the community was the importance of ensuring the compatibility of roommates. Wade did not get to choose his roommate and it turned out they did not get along, which was hard on them and the staff. Just like anyone else would want a voice in who they were going to live with, it was the same for Wade. This reinforces a belief that Gwen and Allison share for Wade and his future—the importance in allowing him to make his own choices and have that respected.

“He should never be made to do anything he isn’t comfortable doing,” says Gwen. “As Wade matures, I think he will enjoy more of doing things he chooses to do.”

The biggest lesson Gwen learned was the power of the pen. She believes it was finally when she and Wade’s support circle started writing letters to MPs and everyone else they could think of that resulted in action. If she had known the impact it would have, she would have started writing those letters much earlier.

But this is often what parenthood is about—learning along the way. For some parents, it took the forced closure of an institution to change their perspective about the benefits of living in the community.

“Many of the parents who protested the closure of Pelican Lake Centre are now very happy about it,” says Nerina Robson of Community Living – Manitoba. “One mother, whose grown child was moved out of Pelican Lake, told me that she never thought in a million years that her son could be as happy as he is now living in the community.”

This is not unusual. Research has shown that a parent’s perspective on institutions changes dramatically to pro-community only after their son or daughter has made the transition. In this way, the family evolves and grows along with their son or daughter, as they engage in the community and outside world.

Soaking in the sunshine

Cathy likes to spend time outdoors. She sits on her swing in the backyard and relaxes in the sunshine. She enjoys fresh vegetables from her garden, as well as the tulips and other flowers that bloom throughout the season in the yard. In the winter, she bundles up in warm clothing and goes out onto the front step. When she gets cold, she comes in to warm up for a while before heading out again for more fresh air.

She hasn’t always been able to indulge this small but important pleasure. Cathy spent most of her life—41 years—in institutions, where she somehow acquired a reputation as a challenging individual. This confounds her current support staff who find that she is thriving in the community. One worker wonders why Cathy had not been asked many years earlier if she would like to move out of the institution or why a life-skills assessment was not completed to determine if she could live in the community with supports.

After leaving the institution, it took time for Cathy to find a living situation that works for her. But she now lives in her own home and while she was not happy at first about having a roommate, she came to enjoy having him around. She will miss him when he moves into his own home but she will also be happy to have her home and staff to herself again!

Being around other people is one of the adjustments Cathy has had to make in the community. While she and her staff continue to work on her comfort level around other people, Cathy has made a good friend, Joanne, with whom she likes to spend time.

Cathy is known for her wonderful sense of humour and love of music, particularly Celtic and country & western songs.

“It’s such a joy to see her dance and listen to her hum along to her music,” says a support worker.

One of Cathy’s greatest pleasures is being able to look outside. If the curtains are closed, she will quickly open them again. She is able to help herself to a beverage or snack, and is working with staff to become more independent around her home.

Seeing life clearly for the first time

Life is much clearer for Cathy now, too. She recently got glasses, which it turns out she has needed most of her life. She loves them so much that staff has a hard time persuading her to take them off to sleep. As one worker noted, it must be wonderful for Cathy to finally be able to see and experience life all around her.

During the week, Cathy enjoys the day program at the local Association for Community Living, where she works at recycling, has coffee with friends, and joins in other activities. She misses it terribly on the

weekends. On Sundays, she attends a local church.

Summer is a favourite time for Cathy with its special activities and trips. The last few years, she has enjoyed holidays at Wellman Lake with staff in a rental cabin for three nights and four days. She goes to a local rodeo in the summer and on July 1st goes to watch the Canada Day fireworks along with others in the community. There are also picnics in the park and time spent with one of her support worker’s family on the farm, which Cathy enjoys immensely.

This is dramatically different from Cathy’s daily routine when she lived in an institution. While there, she would typically sleep in and spend the rest of

the morning on the ward, lounging on the couch or watching other residents and staff in the hallway. Afternoons were spent mostly in the occupational therapy department where she was not engaged in any program and evenings were spent in the ward, sometimes watching TV. Bedtime was early, usually between 7:30 and 8:30 p.m.

Strangely, none of her staff workers understand why Cathy was placed in an institution in the first place or why it took so long for her to be moved out into the community.

Opening up to life in the community

“I have seen so much improvement in Cathy since her arrival in the community,” says Cheryl, one of her support workers. “At first, she was very cautious of the people working with her. She spent most of her time in bed and wouldn’t leave the house. Now she is going out regularly to spend time at the Resource Centre. She has made many friends but John remains her favourite. She gets very excited whenever she sees him. He thinks she is the prettiest girl around.”

Carol, also a support worker, thinks the biggest change for Cathy is having a say in what’s going on in her life. “I’m not sure if she had that freedom before. She seems comfortable and happy. She’s more open to people.”

Cathy has had a PATH (Planning Alternative Tomorrows with Hope) plan prepared, which is implemented by staff and reviewed regularly to help Cathy achieve her goals and lead a happy and rich life.

“I think she feels now that this is her place and she knows what she wants in her home,” says Sandra, another support worker. “The PATH planning was great. It helped me understand better what Cathy’s potential could be. I think the community has been quite friendly towards her and will continue to become more friendly as she gets out more.”

(Names have been changed to protect privacy.)

More alike than not

This is a story about two people—Ron, a fellow who grew up in an institution, and me, a woman, who did not. My friend Ron is struggling right now. He is awaiting surgery, does not have a job, and is looking patiently for qualified staff to help him fulfill his dreams. Some might wonder if going back into an institution would help solve these difficult problems for Ron. There would be staff in place and some sort of scheduled daily routine. All of his daily worries would be looked after, dealt with by the structure and staff of the institution.

As for me, I am doing okay. The flu is sweeping through my house, an uncle is dying in the hospital, and another close

family member was recently diagnosed with a serious heart condition. Does it enter my head (or would it yours?) that maybe living for a few years in an institution would take care of all this for me? Maybe if I stayed a lifetime, I could avoid *all* the trials of life. But would I really want to? What would I learn? How would I grow? It's strange, because we would not think of this option for ourselves. So why does it enter our heads to suggest it for others?

I have had lots of friends who have called and offered to take my four-year-old when I have a cold and lie on the couch. My mom sends over supper. My entire family rallies around the hospital bed of my uncle, reminiscing and reconnecting. Plans are discussed and tears are shed as we process the new information about the heart condition of another family member.

Things are no different for Ron. His friends have rallied around him as he awaits surgery. A friend's mom has offered her time and support as an experienced nurse, to help Ron feel more at ease. Friends are stepping in when staffing is short. His natural support network is exploring with him his new dreams and desires to find meaningful roles to fulfill during the day. Ron is learning that he is loved, that he is worth our unpaid time, and that we will be there when things get tough. It sure sounds like real life to me.

And despite all the trials that Ron is undergoing right now, he is determined to speak up about his life in the community. That is difficult for him, because he cannot speak and uses an outdated communication board. The limited amount of community funding means that things like a computer to help him get his point across are simply

not available, apparently. Maybe Ron could have \$5,000 out of the \$40 million to upgrade the Manitoba Developmental Centre (MDC) so that others could hear his perspective on institutional living. He was adamant about having someone—especially important decision makers—hear how he feels about how his opportunities are different in the community. He wants others to know that he has friendships that make his heart feel good, that he gets support from community programs, that he finally has the chance to meet someone and get married. He wants a regular life just like the one all of us take for granted.



Ron and Charlene, a resource worker

In spite of Ron having to use a wheelchair for mobility and being dependent on

others for much of his personal needs, he is his own boss—he makes his own decisions along with his friends and he has the freedom to make mistakes. He sleeps in his own bedroom and feels he is listened to and respected. He does not feel that was the case when he lived in an institution. Do caring, skilled people work there? Of course they do. But it is about perception. If others have the power to make decisions for you, design your day and hand out your allowance when going on an "outing," how respected could you possibly feel? According to Ron, not very.

The thing that amazes me most is Ron's constant desire to be in a relationship, to find the right woman. He never gives up. He asks people out, he invites them over. He is always on the lookout for Mrs. Right. But it isn't only an intimate relationship that he is after.

He is always working on how to make and maintain friends, and how to enjoy a working friendship with his staff. He is learning from those who love him how to work through disagreements and how to handle it when someone makes him mad.

As for me and my relationships? My husband and I are working through a book on intimacy to try to stay close given that we have three kids in the house. My friendships are diverse and rich and take a lot of work to maintain, and I continue to struggle with how to connect with my four-year-old "spirited" child. I need my friends to continually talk me through ideas and strategies so my daughter and I can stay close. Notice anything?

Ron and I are much more alike than we are different. If I wouldn't want to live in an institution, why would he?

Existing Community Agencies

Westman Region

- Association for Community Living (ACL) Brandon
- ACL Virden
- Baldur Group Homes
- Boissevain Association for the Handicapped
- Brandon Community Options Inc.
- Career Connections Inc.
- Columbian Apartment Program
- Community Respite Services
- COR Enterprises Inc.
- Family Visions
- Frontier Trading Company Inc.
- Kel-Chris Inc.
- Parkland Regional Community Linc Inc.
- Rollingdale Enterprises
- Southwest Community Options
- Spirit Sands Support Service Inc.
- Touchwood Park Association
- Westman Coalition for Employment Opportunities

Parkland Region

- ACL Swan River
- Focus on Employment
- Grandview Residential Services Incorporated
- PRVSI
- R.O.S.E. Inc.
- Samtak Co-op Inc.
- Swan Valley Advocacy Services
- Winnipegosis & District Residential Services

Central Region

- Altona & District Association for the Mentally Handicapped
- Gateway Resources
- Kin Glen Community Residence
- La Residence de Lourdes
- Mountain Industries
- Pine Creek Community Residence
- P.K. Apartments Inc.
- Portage Association for Community Living
- Portage ARC Industries Inc.
- Rainbow Residence
- Residence St. Claude Ltee.
- S.A.M. Inc.
- Somerset Villa Inc.
- Sprucedale Industries Inc.
- Valley Rehabilitation Centre Inc.

Winnipeg Region

- Access Point West
- AMBA Homes Inc.
- Arcane Horizon Inc.
- Autism Society of Manitoba
- Cerebral Palsy Association of Manitoba
- Community Living Winnipeg
- Community Respite Service Inc.
- Community Venture - Salvation Army
- Comspan
- Continuity Care
- D.A.S.C.H. Inc.
- Doray Enterprises
- DOVE Homes
- Eastside Thames
- FASD Life's Journey Inc.
- Hope Centre Inc.
- Hope Centre Residential
- Independent Living Resource Centre
- Intervention Manitoba Inc.
- L.I.F.E. Inc.
- L'Arche
- L'Avenir Cooperative Inc.

Existing Community Agencies

(Winnipeg Region cont'd)

- Luther Homes Inc.
- Manitoba Brain Injury Association
- Manitoba Foster Family Network Inc.
- Manitoba Down Syndrome Society
- MBS Residence
- Mennonite Central Committee (Manitoba) Inc. - FASD Program
- Network South Ent. Inc.
- New Directions for Children, Youth and Families
- Norshel
- Oberlin House
- Open Access
- Open Arms
- Opportunities for Independence
- Prairie Places
- Premier Personnel
- Proactive Employment & Community Connections
- Pulford Community Living Services
- Reaching E-Quality Employment Services
- Rehab Centre for Children
- S.P.I.K.E.
- SCE Lifeworks
- Shalom Residences Inc.
- Simaril Inc.
- Special Olympics Manitoba
- St. Amant
- St. James Assiniboia Industries
- Stradbrook Residential Services
- Transcona Springfield Employment Network
- Versatech Industries
- Visions of Independence
- WASO Inc.
- Westwood Vocational Centre
- Winnserv Inc.

Interlake Region

- ACL Interlake
- ACL Selkirk
- Cornerstone Enterprises
- Hearthstone
- Heima Er Best Inc.
- Interlake Employment Services
- Riverdale Place Homes Inc.
- Riverdale Place Workshop Inc.
- Riverton Care Services Inc.
- Tayside Community Service
- Teulon & Area Advocates for Active Living
- Walske Residence

Eastman Region

- ACL Beausejour
- ACL Red River
- ACL Steinbach
- Dawson Trail Opportunities
- Eastman Employment Services
- El' dad Ranch
- La Residence de St. Malo Inc.

Nor-Man/Thompson Region

- ACL Flin Flon
- Cambridge Residence
- Haldisse CS Fischer Place
- Haldisse Community Service Inc.
- Juniper Centre Inc.
- Norman Community Services
- Society for Manitobans with Disabilities - Northern Regional Office
- The Pas Association for Human Development Inc.
- Thompson Supported Employment Program

A Community Perspective

(The following information was drawn from a December 1, 2000 article published in the Swan River Star & Times, and from employees of the local Association for Community Living.)

In September 1965, the first group home in Manitoba for children with intellectual disabilities opened in Swan River. Called Lion's Manor, the group home was built with matching \$25,000 contributions from the Lion's Club and the provincial government.



Original Lion's Manor group home in Swan River

In the late 1960s, the home was closed for one and a half years due to lack of funding. Public pressure persuaded the provincial government to re-open Lion's Manor as a residence for 18 adults.

The intent behind Lion's Manor was to allow adults with intellectual disabilities to continue to live in their community rather than being forced to live in an institution.

However, the community living philosophy evolved in the 1970s towards smaller homes in residential settings with a maximum of three to four people. This led to the opening of a group home for four adults in Swan River in the 1970s. Another small group home opened in the 1980s and an apartment living program began.

This change in philosophy led the provincial government to decline a request by the Association for Community Living - Swan River in 1988 to renovate Lion's Manor. Instead, additional smaller homes were purchased within the community to accommodate the people living at Lion's Manor.



Examples of smaller homes for in Swan River (above, lower right and below)



I am your **neighbour, co-worker and friend**

Community Living - Manitoba
(204) 786-1607

While it was feared that the residents would not want to leave Lion's Manor, as it had been their home for many years, this was not the case. The residents embraced living in the community and the community of Swan River welcomed them into their neighbourhoods.

"It has been an absolute success in Swan River," says Nerina Robson of Community Living - Manitoba.

Lion's Manor closed in 2000 and the building was sold. It was one of the last large group homes to close in the province.

Deinstitutionalization – Things We Want

1. Establish a Deinstitutionalization Task Force that reports to the Premier, Minister of Family Services & Housing, and Minister Responsible for Disability Issues.
2. Seven appointments must be mutually agreeable to Government and Community Living - Manitoba.
3. A current MLA and/or NDP Party member official be appointed as chair.
4. Task—what are the best living arrangements for 402 people currently living at MDC.
5. Report in 8 months from starting date.
6. Adequate resources at the Task Force's disposal to function and do their job – standard per diems for similar committees.
7. Ability to invite specific people to talk / consult with the Task Force.
8. Ability to do public consultation.
9. Moratorium on all building plans (no tenders) until the Task Force has completed its work and the Premier decides on the next step.
10. No new admissions to MDC.
11. That all elements of the Government Plan released on December 10, 2004, by Minister Melnick, including the 106 pages of the GBR study that won't be released under Freedom of Information, be disclosed to the Task Force. All relevant planning information used to create the December 10 decision be disclosed to the Task Force.
12. Utilize the willingness and expertise of community agencies.
13. That the Community Alternative Proposal be made available to the Task Force.
14. That departmental analysis of the Community Alternative Proposal be made available to the Task Force.
15. The Accelerated Pace Committee continue to do their work in 2005-2006 and plan for beyond 2006.
16. Assurance that MDC is not being planned for long-term use as a facility to:
 - 1) House people living with FASD.
 - 2) Be an alternate to jail for people with intellectual disabilities in conflict with the law.
 - 3) House people with disabilities from reserve communities.
 - 4) House individuals with psycho-geriatric needs in other parts of the region/Manitoba.
17. Expertise from outside of Manitoba be utilized to consult on specific situations / people at MDC who have complex needs.
18. Community Living - Manitoba has offered to bring consultants to Manitoba at their cost to assist.
19. Identify a range of assistance required and create a schedule. This could assist the Task Force.
20. Explore ways the Federal Government can assist the Manitoba Government to accomplish significant downsizing or closure, e.g. a Community Transitions Fund.

A Decision That Needs Rethinking (cont'd)

throughout this country are not solid enough for a variety of political, social and economic reasons. It is time to stop using these excuses to prevent us from creating the necessary planning supports and needed community supports and services to enable their return to their rightful place in the community.

We have learned that:

- 1) People with intellectual disabilities, when asked, choose not to live in institutions. A choice most of us would make.
- 2) Institutions deny people basic rights of citizenship, personal control, decision-making, and a sense of independence. Based on personal stories, as told by people who have lived in these facilities, we know of the abuse, isolation and personal suffering that more often than not occurs in there.
- 3) Limitations usually associated with disability are as much related to the surrounding environment and rules of society as they are to the individual.
- 4) People, regardless of type or extent of disability, do not need to live in institutions.
- 5) Providing service in the community is no more expensive, on average, than that provided in an institution.
- 6) People flourish and thrive when they live in the community, either independently or with support.

The Community Living movement in Manitoba consists of individuals, families, community members, agencies (including 105 groups in 40 Manitoba communities who provide and support community options), and over 3,000 staff who work every day to encourage choice, participation and life in the community.

We feel that the Provincial Government is misdirecting funds with its \$40 million plan to rebuild Portage institution. **The plan unveiled on December 10, 2004, by Family Services and Housing Minister Christine Melnick is not in alignment with other decisions and directions taken.**

- 1) It is contradictory to the NDP's own "Full Citizenship Report of 2001." The Government overlooked consulting with the Disability Issues Office. There was no community consultation with people with knowledge and expertise on this issue.
- 2) It is contradictory to the March 18 Resolution of the NDP Policy Convention in Brandon, which urged the Government to:
 - a) reconsider the decision to spend \$40 million at MDC; and
 - b) reconfirm a commitment to community living.
- 3) It ignores the opportunity to invest in 42 agencies and determine how to support 402 persons in the community. The Community Alternative Proposal—submitted February 2005—has been ignored. Community groups are ready to serve and support people. We can figure this out together—government and community.

Community Living - Manitoba (on behalf of a coalition of agencies and groups) recently wrote the Premier on April 15, 2005, to invite the establishment of a Task Force to work

through this issue with a focus on what's best for 402 people. We have heard of no action being initiated.

All 402 people living with an intellectual disability at MDC deserve dignity, privacy, choice, encouragement, support, and self-determination. And, they have the right to experience this sooner than later. The government's proposal to move 15-20 people out

over the next year or so still leaves an inordinate number of individuals inside MDC without much hope.

A Deinstitutionalization Plan must ensure that people have:

- 1) The right to choose where they will live and with whom.
- 2) Services/programs that are directed and controlled by the person and that are respectful of their right to make choices and take risks.
- 3) The right to individualized living arrangements and control over the required individualized funding.
- 4) The necessary disability related supports needed to fully participate in the community.
- 5) Support, as required, from friends/family/advocates necessary to assist in decision making (i.e. supported decision making).
- 6) Services that meet all of their needs and are high quality, portable and accessible.

It is interesting to note and underscore that these are consistent with the principles of the *Vulnerable Persons Act* and the principles of the Full Citizenship Report. These are the policies of the Provincial Government and Legislation of our Province

\$40 million capital invested differently could equal a personal home for every person. If a shared model is chosen, a real cost savings is realized to the taxpayers of Manitoba. The \$28 million annual operating budget from Family Services and Housing plus unknown expenses that are in Government Services budgets to operate the Manitoba Developmental Centre could be spent differently.

We can create an alternative to MDC – 402 people can live in the community.

What is needed is the political will:

- ◀ To move forward rather than retain the status quo or consider moving backwards.
- ◀ To create a commitment to spend \$40 million differently than the plan announced on December 10, 2004, by Family Services and Housing Minister Christine Melnick.
- ◀ To design a process to plan and engage community leaders—the suggested Task Force would be helpful.

We wouldn't build an orphanage or residential school and we, in 2005, shouldn't build an institution that is clearly outmoded and flies in the face of community wisdom.

It is time to reframe our thinking. When we change the way we look at things, the things we look at do change.

