

Championing the end of institutional residences

Posted By **MAGGIE RIOPELLE**

Never again will someone have to feel imprisoned because of an intellectual disability.

As of March 31, the last three residential institutions for adults with developmental disabilities in this province will close.

For the people who have experienced that isolation, the feeling of being punished, the abuse at the hands of those who were supposed to care for them, it couldn't have come soon enough.

It's a victory in a battle that has been fought for nearly 60 years in this province. Locally, Community Living Welland-Pelham intends to celebrate that victory.

"It should've happened a long time ago," said Community Living Welland-Pelham executive director Barbara Vyrostko. "Over 50 years ago, institutions was one method of support. There weren't the type of supports available as there are now. Families didn't have options."

Board member Maureen Roy concurred.

"Families thought they were sending them somewhere safe," she said.

"It's so frustrating for families because people judge the families ... The lives that were wasted, it's such a pity."

Families, said Vyrostko, were told by medical professionals that institutionalizing their loved ones was the best option to ensure they received proper care.

But sometimes, professionals are wrong, she said.

"Families were told this made sense, it was the best thing for their relative ... this is gong to make things better. When people are isolated ... sometimes bad things happen and the risk of abuse is higher," said Vyrostko.

Jessie Diane McLean spent time in a institution in Orillia. At age nine, she was taken from her family and wasn't released from the system until she was 24, in 1971.

She grew up in shared bedrooms, sometimes as many as 14 girls in the same room. She didn't have her own belongings, such as a television.

She was stripped of the ability to make her own choices.

On one occasion, she was told to tuck in her blouse. Complying too slowly, a staff member hit her on the back with a tennis racket.

All those 15 years, McLean was separated from her family and the community.

"There's a long history of people being taken away from their families," said Vyrostko.

"From age nine to 24, that's during an important time, a time when people start building connections in their community. Those years are lost for people who live in an institution. And closing institutions means that doesn't happen anymore."

Phyllis Burtch ended up in an institution as a teenager, from the age of 16 until she turned 21.

"When I lived in an institution, you didn't get support," said Burtch. "You sit around and do nothing. You feel like you've done something wrong."

Vyrostko said, "It's like being sent away because you don't belong. Like being sent to corrections or prison."

Burtch said there was a time where she was setting the table while living at the institution and she suffered a burn on her arm when someone bumped into her carrying something hot. She told a staff member that she had been hurt.

"I thought no one would believe me ... I was burnt, no one seemed to care. If it happened to you how would you like it?"

It wasn't until two weeks later, when a doctor was seeing another patient, that Burtch went to have it looked at. The doctor, she said, told her it was almost healed and to make sure it was kept clean.

After leaving the institution, it took her a long time to start trusting people, to speak up for herself and to turn to others for support in times of need.

For Maureen Todd, the permanent closure of institutions in the province is welcomed news because no one would ever want to experience life within such walls, she said. She spent her teenage years institutionalized, from age 12 to 18. There was a time when at the facility there were rules that just didn't make sense and made life difficult for those at the institution, Todd said. If someone was a bit late for dinner and arrived after everyone else had said grace, they would be told to leave the table because they didn't say a prayer with everyone else.

"The rest were done eating and they give you nothing. They let you starve until the morning," she said. "They don't treat you right."

There are numerous stories of abuse, neglect, disrespect and indignity that people have suffered. It wasn't uncommon, said Roy, for women and men to be sterilized, without even knowing what medical procedures were being done to them. After leaving the institution they would get married and learn they are unable to have a family.

"It's so barbaric and to think that happened in our lifetime," said Roy.

Community Living is an organization that was founded by parents and concerned citizens who believed the community offered a better life for their loved ones.

For the past 60 years, Community Living associations have worked with families, people who have intellectual disabilities and advocates to build community supports and push for the closure of institutions.

"For 30 years we have been helping people leave institutions," said Vyrostko.

Over that time, while some people were taken out of a facility, others were being put back into the system.

Now, that's all going to change.

While there will never be enough supports in place, she said, even without any supports institutions were just "wrong." And not just for people with intellectual disabilities, but those with mental health issues and seniors as well.

"I say there aren't enough disabilities to go around," said Roy. "If every family had a loved one with a disability ... there would be the political will to make things happen."

McLean, Burtch and Todd are all contributing members of the community. They have jobs, volunteer and raise awareness about the need to close such facilities and the importance of inclusion, not exclusion.

Burtch is president of the Welland chapter of the advocacy group People First, a national organization made up of people who have been labelled as disabled who want their voices to be heard.

"Too often, across history, that voice wasn't heard," said Vyrostko.

For Burtch, knowing that now she can help others, offer support and speak up for them is something she cherishes and would've never been able to accomplish had she still been living in an institution.

"One thing that makes me feel good is helping other people who need more support," said Burtch. "So many people don't care -- it has to stop."

For Todd, life in a community setting has given her the chance to discover she can accomplish so much more than she ever imagined. And that, she said, makes her very proud of herself.

"My family gets to see the difference, too," she said. "They are proud."

Community Living plans to celebrate on March 31 with about 35 people who have come from life in an institution. They will also be putting up a waterfall fountain at its Sutherland Ave. home and, to honour them, include the names of people who once lived in an institution.

"Part of the celebration is that we don't forget," said Vyrostko. "The journey hasn't ended."

Said Roy: "One small step for man ... one giant leap has yet to come."