

Does anyone care for the disabled?

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Chris Mikula, The Ottawa Citizen

Rita and Bob Burns, both 85, worry about long-term care for their developmentally-disabled daughter, Maureen, 56, who has lived with her parents all of her life.

It's not that Rita and Bob Burns want their daughter to leave home, but they're 85 and they realize they won't be around to take care of her forever.

"We'd like to see her settled in a place where she's satisfied and where we're satisfied before we, um, depart," says Rita.

Maureen Burns has lived with her parents for all of her 56 years. The second-eldest of five kids, she contracted encephalitis as a baby. The illness led to serious physical and mental impairment.

Still, Maureen lives a full and active life. She has a job at an employment service for the developmentally-disabled: "We put paper into envelopes and we seal them."

She goes bowling, belongs to a social club, plays computer games and enjoys music -- "I just lo-o-ve Barry Manilow."

But Maureen needs a lot of help. She walks with great difficulty and needs a wheelchair outside the home. She frequently falls.

"If Maureen falls, it takes the two of us to get her up," says Bob.

For the last decade, the family has gotten help from Ottawa's homecare program, including twice-weekly baths. Since 2002, homecare has come daily.

There's a baby monitor in Maureen's room so that her parents can respond in the middle of the night. But they don't always hear her cries for help; their hearing isn't as good as it once was.

"I went to the bathroom in my bed a few times," she says. "When no one came."

Three years ago, Rita was diagnosed with operable cancer. Then, a friend had a stroke and was no longer able to care for a severely-disabled son. Rita and Bob realized how quickly things could change.

Maureen is on a waiting list for round-the-clock care in a residential setting. While she is quite independent, she can not be left alone. "I'm not allowed near the stove," she says wryly.

The Burnses are tired of waiting. Working with five other families in similar circumstances, they submitted a plan to the Ontario government a year ago for a supportive-housing project. It's under the umbrella of Christian Horizons, which runs residential programs for the developmentally-disabled in Ottawa.

The families dubbed their proposal "Project 13;" it would be the 13th Christian Horizons program locally.

They offered to set up and furnish supportive-living apartments if the government provided operating funds. A year later, they have not heard back. One of the parents in the group died a few weeks ago.

The lack of community-based services is at the core of the debate about what will happen to hundreds of developmentally-disabled adults scheduled to be released from the Rideau Regional Centre when it shuts down in four years.

Opponents of the closure plan say the institution's residents have severe disabilities and need highly complex care. A class-action lawsuit has been threatened to stop the plan.

But moving residents into the community has also won praise from an eclectic range of supporters, including an opposition MPP and disability rights activists.

"We are finally witnessing the end of an era in which persons with developmental disabilities were isolated and denied the opportunity to live in the community," says Patricia Parker of Citizen Advocacy, an agency that works on behalf of the disabled.

But for the closure plan to work, Queen's Park needs to move quickly to eliminate waiting lists and bolster community-based services.

The six families behind Project 13 have spent the past year shuttling from office to office trying to convince bureaucrats and politicians to approve their plan.

"We have no idea why it's not being funded," says Ann Burns, Maureen's sister. "They haven't told us if there's anything wrong with the proposal."

Ministry of Community and Social Services spokeswoman Anne Machowski says officials in Toronto referred the families' proposal to officials in Ottawa. Officials here referred inquiries back to Toronto.

"Well, it's not a 'no'," says Ms. Machowski.

Stories like Maureen's are exactly what make Marjory Lalonde worry.

Mrs. Lalonde's 43-year-old daughter, Tracy, is scheduled to leave Rideau Regional in 2008. Tracy has cerebral palsy, can't speak and can't feed herself. "She is severely retarded -- they can call it 'developmentally-disabled' -- but she's really retarded."

Mrs. Lalonde, 71, has high blood pressure. Her husband has dementia. Like Bob and Rita Burns, she is acutely aware of the fact that her daughter will outlive her.

"If something happened to me, I don't have to worry so much about her -- she's safe there (at Rideau Regional); she's comfortable there.

"They would have to prove to me they have something better. And I think they will have a hard time doing that."

No matter how hard, Queen's Park must meet that burden of proof. Ironically, the waiting lists and lack of services are a by-product of decades of putting developmentally-disabled people out of sight. Invisible issues don't get a lot of attention in politics.

But fear will continue to surround the Rideau Regional closure because many relatives lack the confidence that those better community-based services will be in place. If services aren't available for relatively independent people, what about folks like Marjory Lalonde's daughter?

Reflecting on nearly six decades of taking care of their disabled daughter, Bob and Rita Burns say public attitudes have improved tremendously.

"We used to just hide people away," says Rita.

But it's tough to listen to aged parents, often ill themselves, talk about how worried they are for their kids. It's hard not to wonder whether we've actually made as much progress as we think.

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