



Tracie Sheppard, far right, hangs out with her friends outside their rental apartment in Surrey.

RAFAL GERSZAK/THE GLOBE AND MAIL

## As parents grow older, finding accommodations for disabled children becomes a daunting challenge

[FRANCES BULA](#)

SPECIAL TO THE GLOBE AND MAIL

LAST UPDATED: FRIDAY, MAR. 24, 2017 10:13PM EDT

3 Comments

Marie Sabine has spent years worrying about where her daughter will live and what kind of help she will get as both of them get older and, eventually, Marie dies.

Her daughter, Tracie Sheppard, now 48, was born with a rare genetic abnormality called Cornelia de Lange syndrome, which resulted in both physical and mental impairments. She will need her own place, one where she gets support, for life.

She is part of a new generation of people with similar issues who can no longer easily be shipped off to institutions, group homes or home shares – the solutions of the past.

“Now they want to be on their own,” Ms. Sabine said.

And Ms. Sabine is part of a new generation of parents in B.C., Alberta and across the country who have to scramble for new solutions as they deal with the fact that their children will likely live long after they and the resources of their estates are gone.

The future is particularly problematic in B.C., where housing costs are so high in many cities and even middle-class couples earning decent salaries cannot find affordable places to buy or rent in the Lower Mainland.

Not only is the amount of money given to people with developmental disabilities for housing a complete mismatch with local rents, but BC Housing – the agency that oversees subsidized housing in the province – does not consider them at risk of homelessness, so they get low priority in the system, Ms. Sabine said.

Challenges also exist even in places such as Alberta, where rents are lower and the province provides substantially more money to people with disabilities than B.C. does: up to \$1,588 a month per person, with \$700 of that for housing, compared with \$1,033 in B.C., with \$375 for housing.

A common solution in Alberta is home sharing, where the disabled person lives with someone who gets payment for room and board and support help.

“It’s trying to find enough people who are willing to take someone with a disability,” said Helen Cowie, the CEO of the Developmental Disabilities Resource Centre of Calgary. “It can take several months for a family to find something. It’s not the same as a job. You’re taking someone into your home.”

Even though group homes and home-share remain an option in B.C., people there say their children prefer independent living.

Ms. Sabine found a partial solution when the Semiahmoo House Society built a 71-unit complex in White Rock called Chorus Apartments that has 20 units for people with developmental disabilities. Her daughter got one of them.

But there was still a problem. Even though the society’s rents are modest at \$850 a month, they far exceed the disability allowance of \$375, so parents had to add nearly \$500 to other expenses they cover.

“I’m 69. Some parents here are in their 70s,” Ms. Sabine said, sitting at the kitchen table of Ms. Sheppard’s tidy apartment, filled with framed pictures, ornamental china, and tasteful furniture. Her daughter listens attentively as her mother speaks. “We have to think past our children living at home to the future.”

The Chorus Apartment arrangement also still required enormous sacrifices from parents. One couple sold their house in Surrey and moved to Yarrow, where they could buy more cheaply, to secure a long-term lease for a child, forcing them to commute huge distances to visit. Another has recently started cashing in RRIFs to pay their daughter’s rent.

Ms. Sabine and other parents who have children living in the complex scored an exceptional triumph on Friday in their long-running bid to get BC Housing to provide rent supplements.

After months of rejections and appeals, and just days after The Globe and Mail contacted BC Housing to ask about the issue, the provincial government announced it will give the complex \$75,000 a year for the next 10 years as a rent supplement. However, the disabled residents cannot keep the financial assistance if they move, as the parents had wanted.

The group started lobbying BC Housing last year for portable rent supplements, which the agency has generally not provided. When they were turned down, they appealed and, two weeks ago, filed a complaint with the provincial ombudsperson’s office.



Marie Sabine, left, visits her daughter Tracie Sheppard at her rental apartment in Surrey. 'We have to think past our children living at home,' Ms. Sabine says.

RAFAL GERSZAK/THE GLOBE AND MAIL

During that process, they met with met with Gordon Hogg, an MLA with the governing BC Liberal Party.

"It will improve the affordability of this development," Mr. Hogg said of the funding. "This will take the parents out of having to subsidize."

But hundreds of parents in B.C. – hard-working advocates who have not marshalled the kind of campaign Ms. Sabine and her group did – are not better off than before.

Mr. Hogg acknowledged this is a province-wide problem and that this case has prompted BC Housing to look at the issue again.

Ms. Sabine said some pre-election campaigning was likely going on, but she hopes "it's cracking open a door" at BC Housing.

In all the months up until now, that door seemed to be quite shut.

All indications the parents got in earlier exchanges with BC Housing, Ms. Sabine said, was that it was unwilling even to consider the rent subsidies because it could lead to "thousands at the gate" adding yet more stress to its struggles to house the homeless and seniors.

But there are problems beyond BC Housing, say parents who navigate the bureaucracy for their children.

They include people like Barb and Mike Schultz, who are in their 50s and have just started trying to figure out what kind of housing their son Matthew, 19, will need for rest of his life. The youngest of four boys for the Saanich couple, she a pharmacist and he a federal employee, Matthew has autism and a moderate-to-profound cognitive impairment.

Before he turned 19, they got support from the Ministry of Children and Family Development. But two years ago, they knew they needed to start negotiating with the Crown agency that assists disabled people, Community Living B.C.

The agency does not provide housing, but its decisions about what extra supports to give people wherever they live shape parents' options.

CLBC will spend \$954-million this year to help 20,000 people, including 7,600 getting residential services – a mandate that makes for some fractious relationships with parents. Ms. Schultz said a CLBC facilitator essentially told them Matthew could not get housing because he could live with his family and that CLBC would not provide living support for the same reason.

But Ms. Schultz, like many others, said provincial agencies cannot just rely on families.

“We need to be able to move on and retire. It ends up being medically difficult for parents as they get older to do this.”

Ms. Cowie, running a resource centre in Calgary, echoes that point.

“The parents are going to die. When the family dies, if you haven't helped the person with a disability, now they're not able to live in the community.”

She said the issue is getting more acute, because disabled children are living longer and developing additional problems, such as Alzheimer's disease in their 40s.

In their quest to set their son on a path to live on his own some day, the Schultzes spent \$70,000 to renovate their basement so Matthew can live independently in the suite for at least a few years before they try moving him into the community.



Tracie Sheppard arrives at her rental apartment in Surrey, British Columbia, Monday, March 20, 2017. Tracie's mother Marie Sabine is among parents who are struggling to find housing and get more provincial support for their adult children with developmental disabilities that live in rental housing.

RAFAL GERSZAK/THE GLOBE AND MAIL

But they told CLBC their son might endanger himself if it did not provide some support in this.

“We basically came down to months before he turned 19, we had to admit he was going to be in crisis.” (During a similar showdown in Ontario two years ago, one mother had her son officially classified as homeless in an attempt to get him some supports.)

Ms. Schultz said a regional manager asked her and her husband if they were just absolving themselves of all responsibility as parents.

But the Schultzes did not back off, and the agency eventually agreed to provide Matthew eight hours a week of living support – helping him learn how to clean, cook, manage his money (he stocks shelves two hours a week at a nearby grocery, in addition to his disability allowance), and generally survive.

“Yes, he’s in the house, but he’s independent. And the reality is he’s 19, he wants to do what he saw his brothers do and live on his own. We’re going to stop being his full-time caregivers.”

Angela Clancy, the executive director of the Family Support Institute, which works with families of the disabled, did a quick survey of parents across the province for The Globe to get their thoughts on the system.

She got responses about expensive rents, landlords who do not want tenants with disabilities, a lack of any housing options in their community and, particularly, the mindset of CLBC.

Faith Bodnar, the head of the non-profit Inclusion BC, summed it up in an e-mail:

“The system is set up to keep people out and support them only when there is no other option. This pushes people into crisis.”

CLBC’s CEO, Seonag Macrae, said the agency inevitably sees unhappy parents because “sometimes, we can’t do everything.” She added that a conversation may come across negatively when it is not intended that way. “It’s an interpretation of messaging.”

But Ms. Macrae said the agency knows it needs to make changes because people with developmental disabilities now want to live more independently.

CLBC just started conversations last year with BC Housing and developers about including units for the developmentally disabled in their projects.

Some parents are enthusiastic about the idea of pooling their resources and buying or constructing a building for their children. North Vancouver has one project like that.

But, said Ms. Macrae, CLBC’s goal is not to isolate developmentally disabled people in one building. The agency prefers the Chorus Apartment model that have units for both the disabled and the regular community.

CLBC provides supports to the disabled group living at Chorus, who are among about 1,300 getting assistance in independent units from the agency. Tracie Sheppard, for example, gets up to 10 hours a week of help with shopping (she is afraid to cross the road to the nearby Peninsula Village mall alone), cooking, cleaning and managing her money.

“Our goal is maximizing inclusion and not segregating people into that building,” Ms. Macrae said. “The more people are integrated, the more they develop that independence.”

But CLBC’s goal will likely require BC Housing to provide the same kind of rent supports that the Chorus apartment residents are now getting.

Ms. Sabine said she talked to a non-profit group in Squamish recently that is trying to build a new project and include five units for the developmentally disabled.

The problem? “They got no takers. They don’t have parents who are able to subsidize the rent. It’s not a good way to do business.”

 Report Typo/Error

Next story | [Learn More](#)



### Homeowner hopefuls are fleeing Lower Mainland’s housing crunch

SUNDAY, MAR. 26, 2017, 10:39PM EDT



### B.C. first-time home program attracts more than 1,000 applicants

SUNDAY, MAR. 26, 2017, 8:51PM EDT



### Toronto realtors frustrated by the soaring housing market

MONDAY, MAR. 27, 2017, 5:00AM EDT

X

- 
- 
- 
- connect with us
- 
- 
- 

#### Products

- **The Globe and Mail Newspaper**

Newspaper delivered to your doorstep. [Subscribe to the newspaper](#)

- **Globe Unlimited**

Digital all access pass across devices. [Subscribe to Globe Unlimited](#)

- **Globe2Go**

The digital replica of our newspaper. [Subscribe to Globe2Go](#)

- **Globe Email Newsletters**