

A system that fails troubled teens

By GAYLE MacDONALD, June 27, 2013

One family finds out-of-country help, but most kids with multiple illnesses fall through holes in the health care safety net

Katherine Duff is 16. She comes from a close-knit Toronto family. She has a part-time-job and gets straight As. She loves poetry, watching movies with her younger sister, and going out with friends for dinner or to the mall. She adores animals, especially dogs. And she wants desperately to go to university and become a lawyer. Like her dad.

But for two years, Katherine was locked in a downward spiral of angry, self-destructive thoughts. She heard voices. She cut herself (she has multiple scars on her arms and legs). Diagnosed as bipolar with borderline personality disorder (BPD), she tried twice in the past year to take her own life, both times overdosing on Seroquel, one of six anti-psychotic drugs she takes to regulate violent mood swings. On good days – which for a while were rare – she went to school, worked at a doggy daycare, and baked cupcakes with her mom. On bad days, she shut herself off from society, curled up in bed weeping.

Last winter, Katherine's parents, Cameron and Doris Duff, never left her side. They locked away knives and carefully metered out her medications. And they tried to get their middle child the help she desperately needed, taking her to mental health clinics such as Ontario Shores and Toronto's Oolagen Mental Health Centre and Hincks-Dellcrest Centre for Children and Families. They saw child psychiatrists. They admitted Katherine four times to Sunnybrook's outpatient adolescent centre, where she stayed a week to 10 days at a time. When she'd return home, the vicious cycle would start all over again.

Katherine is one of many Canadian teens whose multiple diagnoses meant that her see-saw emotions were extremely challenging to treat, especially in a mental health system that is over-burdened and difficult for desperate families to navigate.

"The underlying stress of not knowing, day to day, if she's going to be alive, is terrifying," Doris Duff says, her daughter at her side. "It's been hard on our marriage. It's been hard on her older brother and sister. We just wanted to make sure she sees her next birthday."

Like others with children who have complex mental health needs, the Duffs have been on a heart-wrenching journey: long waits for services, shortages of child psychiatrists and a total lack of the kind of intense, residential treatment facilities Katherine needed.

After her second suicide attempt last February, the Duffs followed the advice of a psychologist at Hincks-Dellcrest and admitted her to McLean Hospital outside Boston, at a cost of more than \$70,000 (it was not covered by OHIP). The Harvard-affiliated institution offers a treatment called dialectical behaviour therapy, or DBT. Incredibly, she has been home more than a month now, and Mr. Duff, his voice shaking with relief, says she is "doing amazing these days. It's like she's a different kid."

DBT psychotherapy for teens has been getting increasingly good reviews in the United States and Europe, where the therapy, supported by Buddhist meditative techniques, is more widespread. Mr. Duff says many psychologists here have not even heard of the treatment, which University of Washington psychology researcher Marsha Linehan developed to help people with borderline personality disorder by combining cognitive behavioural therapy techniques and concepts of stress tolerance and mindful awareness. It trains the mind to think differently so that patients can learn to cope with strong emotions, explains Joanna Henderson, a scientist at the Centre for Addiction and Mental Health's child, youth and family program in Toronto.

Very little DBT psychotherapy is available in Canada. Ontario has one private, comprehensive outpatient clinic, Toronto's Broadview Psychology. Katherine is getting weekly follow-up therapy there at a cost of \$240 an hour (also not covered by OHIP). CAMH – which has a DBT outpatient program for young adults over the age of 18 – last year launched a pilot DBT project for youth 14 to 18 in Toronto, Thunder Bay and Ottawa. But CAMH's Henderson agrees DBT options are woefully lacking. "I hope families will have better access going forward," she says, adding: "The [health] ministries are working together more and more to address some of these more systemic issues. However, there continues to be a need to better collaborate so we can provide smoother pathways to care for these youth and their families."

"We literally turned over every rock," Mr. Duff says of the family's search for help. "There is acute care for adolescents in hospital, and long-term stays in mental-health clinics scattered across the province. But there is nothing in the middle ground, and with cases as complicated as Katherine's, early intervention is key. We had run out of time."

Dr. Marshall Korenblum, a Hincks-Dellcrest psychiatrist, said the system is broken and needs fixing. "There is a dire need for more intensive, residential programs here," said Korenblum, who also works at Sunnybrook's outpatient adolescent program. "And the reason we lack them is partly financial. The U.S. has a more integrated model of mental health care. If you try to get a kid into a treatment centre here, there are often exclusion criteria. If you have more than one mental health issue at a time – if a kid has depression, an eating disorder or substance abuse issues – good luck trying to find a centre that will treat all of those."

He points out that Ontario is not alone in this: "In all of Canada, we have a total of 450 child psychiatrists, and only about 140 in Ontario. There are huge waiting lists that can be one to two years long. Once you go outside large, urban centres, it's horrendous."

The Ministry of Health and Long-Term Care turned down a bid for out-of-country funding to send Katherine to McLean (Mr. Duff says he will appeal). The family knows they are fortunate to be able to pay the \$70,000.

Katherine says she would not be here today without their efforts and the intensive therapy at McLean. "I know of so many kids whose parents have sent them to the States, or are soon going to go," the teen says, tugging on her braid and clearly uncomfortable going public. "I wouldn't be here if it wasn't for my mom and dad," she says glancing across the room. "I have other friends who can't go because their parents can't afford it. They're the ones I feel sorry for."

Ontario Health Minister Deb Matthews is trying to reduce the number of youth needing to be treated in the United States, spending more than \$90-million on a three-year plan to improve access to more immediate adolescent mental health care in the province. Her ministry says the number of Ontarians heading to the United States dropped to 78 last year from 100 five years earlier, a drop that cut the cost of the out-of-country program to \$5-million from \$10-million. But while the number of under-18s going to the U.S. for mental health care fell to 43 last year from 58 in 2007, the cost to the province jumped to \$2.8-million from \$2.3-million.

Donna Duncan, chief executive of Hincks-Dellcrest, which helps 8,000 families a year and has been seeing Katherine since January, says holes in the child/adolescent mental health sector need to be filled. "To me, sending a child out of province is wrong. It's hard on the kids and it's hard on the parents. But in complex mental health situations like Katherine's, there really is no choice." Duncan bemoans the lack of transparency and connectivity in the mental health sector, spread out over a dizzying array of 440 children's agencies, 330 community agencies and 150 addiction treatment centres. "We know one in five children nationally will have mental health issues, and right now, four out of five [of them] won't get the care they need."

Katherine started cutting herself two years ago. She knew it was wrong, but could not stop. When one of her many psychiatrists altered her meds, she says an angry guy named Robert ("I'm not sure how I got that name") got into her head, telling her to kill herself "or he was going to kill me." The first attempt was in February, 2012; the second about four months ago. Mrs. Duff recalls having a bad feeling and going into Katherine's room. She found her lying in bed, mumbling about pills. "Once the suicide bug is in your brain, it doesn't go away," Katherine said in an interview last winter. "I tell my friends it's like having a crazy radio in my head. Sometimes it's blaring in my ears and I can't get rid of it. Then it will quiet down. But it's never turned off."

"I've tried it all," the well-mannered teen added. "They send me home, and it starts all over again. I am just really scared. They'd say to me, 'Oh, you've been in a hospital, so that's okay, you've dealt with it.' And I'm like, 'No. I've sat there in a hospital gown for two weeks and I didn't learn anything.' I have no clue how to cope. My options were to be hospitalized or go into a residential treatment centre like Youthdale or Pine River, where I could stay for one to two years. What's in the middle? Why can't I get anything in my own country that's going to help me? I'm tired of feeling like a walking mental illness."

That was before she went to McLean. Now, in the living room of her North Toronto home, she says that, for the first time in years, she has hope of getting better. "I don't feel messed up," says the teen, who has got rid of everything in her bedroom that had "bad associations."

"I'm a completely different person than I was in the winter," she says now. "There is no question McLean saved my life. At McLean, we always talked about the five steps to get out of hell. I used to only look backward, and now I'm finally able to see what might be ahead."