



Centre for Addiction and Mental Health
Centre de toxicomanie et de santé mentale

Dual Diagnosis Program

Dual Diagnosis Real Life Stories

Prepared by
National Coalition on Dual Diagnosis



Developmental Disabilities Section of the
Canadian Psychiatric Association



NADD Ontario

Dual Diagnosis Real Life Stories

David's Story (Ottawa)

Nowhere else to go

It costs \$400,000 a year to keep David Murray in hospital because, as a 'dual diagnosis' patient, he falls into a jurisdictional no-man's land and no one will take responsibility, Laura Drake reports.

Laura Drake, The Ottawa Citizen
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On Monday night, David Murray called his parents, sobbing, to tell them that he wanted to die. The 46-year-old, who suffers from a developmental disability and mental illness, was calling from his hospital bed at the Queensway Carleton Hospital where, due to a lack of resources and funding for people with his condition, he has lived for the past nine months.

"He'll look at us and say, 'You're my parents, surely you can do something about this.' How do you answer that?" his father, Gil, said yesterday.

David Murray is one of at least a dozen people with what is referred to as "dual diagnosis" -- who are taking up Ottawa-area hospital beds because they have nowhere else to go, said Brian Tardif, the executive director of Citizens Advocacy Ottawa.

In light of this week's declaration by Ontario Hospital Association president Tom Closson that a bed crunch is the most serious problem facing Ontario hospitals, Mr. Tardif said it is absurd that dual-diagnosis patients take up short-term beds for months and years at a time simply because of a lack of community support, while emergency rooms become backed up and elective surgeries are cancelled due to a lack of acute-care beds.

"David is a perfect example of somebody who is costing our medical system enormous amounts of money and they are doing nothing for him but giving him a safe place to live and three meals a day," Mr. Tardif said. Mr. Tardif estimates it is costing the provincial government about \$400,000 a year to keep Mr. Murray in the Queensway Carleton.

In contrast, Joyce Lundrigan, a planning facilitator with Citizens Advocacy, presented a plan to the Ministry of Community and Social Services for David Murray that would have seen him released from the hospital into a one-bedroom apartment near a group home with the nutrition and social supports he needs.

That plan would have cost \$85,000, but it was rejected.

The problem, according to Mr. Tardif, is that dual-diagnosis patients have fallen into a no-man's land between the Ministry of Community and Social Services and the Ministry of Health and Long Term Care, with neither really taking responsibility. Since hospital beds are funded regardless of who occupies them, that is often exactly

where dual-diagnosis patients end up after their mental illness triggers a crisis -- and where they stay.

Yet life in hospital often only exacerbates the problems facing dual-diagnosis patients in the first place, Mr. Tardif said.

Before being admitted to hospital, Mr. Murray had held down several jobs for long periods. He was adept at fixing electronic equipment and was learning how to drive a car.

"Here's a guy who has capacities, who has been productive and now just seems to be lost, and he's lost because our community doesn't have the resources to support him and he's stuck in hospital," Mr. Tardif said.

Unable to either read or write because of his developmental disability, Mr. Murray's days are long and tedious.

The last three months have been worse. He's getting more desperate," said his mother, Betty. She'd take him home, but she is simply unable to do it without help, for which there is no funding.

"This has an impact on the family, on his sister, on his brother, on his nephews. We wake up in the morning and where are our thoughts?

"They're with David and it's having, more than I'd like to admit, an impact on us," said Gil Murray. "David's not the only one. If this is the way they're handling everyone, it's wrong."

William's Story (New Brunswick)

Adapted from "*Connecting the dots: A report on the condition of youth and risk and youth with very complex needs in New Brunswick (2007).*" The full text is available at:

<http://72.14.205.104/search?q=cache:jbsHvskp49oJ:www.gnb.ca/0073/PDF/ConnectingtheDots-e.pdf+Connecting+the+dots:+A+report+on+the+condition+of+youth+and+risk+and+youth+with+very+complex+needs+in+New+Brunswick&hl=en&ct=clnk&cd=2&gl=ca>

As a baby, William "was normal as a child can be." He was basically meeting all of his milestones until he reached the age of two. When he reached three, William's parents, concerned about a slowing development, took him to a psychologist, who told them not to worry, that children are often delayed in certain areas. Two more years passed. At five, William was sent by a psychologist to the Isaac Walton Killam Hospital in Halifax. The diagnosis was autism. William's father had never heard the word, and had no idea what it was. Apart from some restlessness, William had exhibited no behavioural problems, or at least nothing the parents couldn't handle.

In a school setting, however, William required many interventions. Although he benefited from an inclusive educational model, he did not, despite the many interventions, progress developmentally much beyond the cognitive or communicative skills of a child of two or three. His behaviour became disruptive, and he had to be removed from the regular classroom for extended periods to an alternative setting created for him. In fact for many years, William spent a great deal of time isolated within the schools into which he was "integrated".

When William was about 19, his psychiatrist prescribed a new medication, which affected him negatively. His seizures became more severe. He was more difficult to manage at home. The parents requested respite care, and William was placed during the day in a Family Care Service (FCS) group care environment. Then he started spending two nights a week at the group home, and eventually he moved there. A few months later, the parents noticed a marked deterioration in their son's behaviour and cognitive abilities. They started noticing burn marks on their son's body. According to the father, they were given inconsistent explanations about the marks. About five months after they first mentioned their concerns, the parents were told William had to leave the home. FCS undertook to find a new placement for William. A few proposals were put forward, but FCS denied these because of the high cost. The group home operator then agreed to place William in an apartment with one-on-one staffing until another placement could be found. In this highly structured environment, his behaviour problems were minimal. He continued his therapy, visits with his family, and schooling. But these interim arrangements could not be extended beyond a few months.

In 2002, when William was 21, FCS advised his parents that he could no longer live in the apartment. The department proposed moving William to Centracare in Saint John. The parents were concerned about this move and requested a 30-day extension of William's stay in the apartment while they explored options and sought expert advice.

The parents presented a report from William's family physician stating that Centracare was not a good placement for William. The doctor said it could cause his

condition to deteriorate. His psychiatrist and his psychologist also disagreed with this move, and so did the staff at Centracare. However, the Minister rejected the professionals' opinions and denied the request for a 30-day extension.

William was sent to Centracare. The plan was that William would be placed in the rehabilitation unit, with a view to one day returning to his community. In fact, he was put in a "sustained care unit" with limited access to programming and therapy. The staff said William was at risk of being assaulted by other residents, a warning supported by an earlier psychiatrist's report. These warnings were subsequently borne out when William was repeatedly assaulted, including a sexual assault.

As a result, William's behaviour deteriorated, and he lost most of the cognitive abilities he had gained during the previous years. His father believes this damage is probably irreversible. In a statement of claim in a lawsuit the parents launched against the Province, they said that, on one visit, they ". . . found William to be heavily sedated, no longer recognizing his parents and lying in his bed with his hands over his ears complaining of the noise. They also found him naked in isolation ...on many occasions afterwards." Sixteen months after his placement at Centracare, William was sexually assaulted. Using any means they could to be heard, the parents continued to advocate for their son to be removed and placed in an appropriate environment.

Three years after being admitted to Centracare, William was transferred to the Spurwink facility in Portland, Maine, at an annual cost of over half a million dollars a year. His parents have no means of transportation to make the six-hour drive to Portland. They are pleased that he is receiving the care he needs, but would prefer that their son could receive this kind of care in New Brunswick, so that they could visit him. When he arrived at the American facility, William was placed in a house where he was, and still is, the sole occupant. Initially, he was cared for by a couple who lived in the house with him. But it was very demanding on the couple, given William's state on arrival, so the arrangement was changed to his being cared for by staff working in shifts.

Spurwink staff told my investigators that according to their information, in his last year at Centracare, William was not once taken outside. It goes without saying that he was, and still is, a long way from his former self. But, in his two and a half years at Spurwink, he has made constant, if slow, progress. Staff working with him have said the following: "William definitely seems to have skills. He picks up on things. The potential is there.... He seems interested in education.... Some methods used with others are not successful with William. But he is starting slowly to show results..."

Roseanne's Story¹

Note: *Roseanne's story is exceptional because it is rare for people with developmental disabilities to be able to express themselves so clearly. Roseanne's contribution is that her story can stand for so many others who cannot tell their own.*

Forty years ago, I was born with developmental disabilities. When I was just six weeks old, I was placed in a foster home. This was supposed to be a temporary placement and the foster family was told I would be transferred to a hospital institution within a week. That never happened. I stayed with my foster family and just before I started school they adopted me permanently.

When I was 5 years old I went to our neighbourhood school on the special "bunny bus." The children at the school poked fun at me and called it the "Nutty Bus." When I had plastic surgery on my ears and had to go to school with my head bandaged for a few days, they were mean and said "Oh, they gave her some new brains." I still remember it.

I was put in a regular grade one class when I was six years old but it was stressful for me dealing with all the so-called normal children. When it was time to go to secondary school, I went into a "special class" where I did very well and was "top dog on the totem pole." Finally I was accepted and I did very well, especially at sewing. After being in that class for 3 years, I realized that I would never graduate and be able to get a job unless something changed. My mother took me and some of my sewing over to the school board and showed them just what some of the developmentally delayed students could do. They were impressed enough to give us the address of a place that made ski wear. I had never even seen a power sewing machine let alone use one but I learned quickly. I was the only "special" worker but things worked out well because the other ladies were all Chinese. I didn't know what they were saying so nothing could hurt me. I stayed at that job until the company went bankrupt.

That didn't stop me. Soon I was working at a veterinary hospital in the morning and a doggy day care in the afternoon. I was managing my life very well and even got my driver's license. When I wasn't working, I was enjoying figure skating and horseback riding and my family life was a happy one.

In my early 30's, the bottom dropped out of everything. The doctor at the veterinary hospital moved to the USA and I no longer had my stable job. Then one of my brothers died. It seemed too much to bear.

I started to think that people were spying on me. I heard voices. One night I started screaming because I was certain that I was hearing the devil telling me to do real bad things. It was very frightening to me and to my family. My mom and sister took me to the hospital where I stayed for 3 months and was diagnosed with manic depression. Mom and my sister and my brother came to see me every day. We would play pool or do puzzles. I was seeing a good psychiatrist and other therapists and counselors and they all really helped me get better.

Once my new medication seemed to be working, I was able to go back home.

¹ Roseanne (2006). In M. Hombert (ed). Success stories from the frontline. Port Coquillam, BC: Friedlander/Donnelly Publishers.

Although I couldn't remember very much, I did remember my bank number and my car license number. I was managing much better. The voices in my head were gone but some things made me very sad. I could not go horseback riding or figure skating because of the medications. The worst thing was that I couldn't drive my car because of the side effects of the medications. I spent most of the day sleeping and gained a lot of weight.

I began regular visits to the West Coast Mental Health Support Team almost five years ago and my life has been continually improving. I sleep well and don't have any more bad dreams. I see my doctor once a month and I am much more active. I am driving my car again and I go horseback riding regularly. My figure skates didn't fit for a long time but, with a change in my medication, I am starting to lose weight and I know I'll be skating real soon.

I am very lucky to have such a loving family and so many other caring people to help me. Now I can really look forward to getting another job working with animals and get on with my life.