Dual diagnosis

Experts believe as many as 50 per cent of children with developmental disabilities may also have mental health issues. But the second condition often goes undiagnosed and untreated, Tralee Pearce reports

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For Tammy Kliewer, learning that her two-year-old son Tavish had autism felt like solving a major puzzle. He had been non-verbal and "very much in a world of his own" his whole young life.

Yet the diagnosis didn't explain his other behaviour: complete meltdowns, violently banging his head and biting his arms. "We could do nothing but restrain him when he went into a meltdown," said Ms. Kliewer from her home in Barrie, Ont.

At about 4, he was diagnosed with a string of mental illnesses: anxiety, obsessive-compulsive disorder and self-injurious behaviour. But not before a number of health-care workers had chalked up his behaviours to autism.

"It was a cop-out to say it's all part of the autism," Ms. Kliewer says. "There's a significant portion of autistic children who never bang their heads or bite themselves."

Enlarge Image

Seven-year-old Tavish Kliewer plays in his bedroom with his sister Macie. He was diagnosed as autistic at age 2, but it took another two years before he was found to also have a string of mental illnesses: anxiety, obsessive-compulsive disorder and self-injurious behaviour. *(JENNIFER ROBERTS FOR THE GLOBE)*

Now, Ms. Kliewer knows that Tavish is one of many Canadians with a "dual diagnosis." The term refers to people with a permanent developmental disability such as autism, Down syndrome or fetal alcohol syndrome who develop a mental-health problem such as depression, anxiety or psychosis.

Some estimates put the developmental disabilities rate at about 3 per cent of the population. Experts believe 38 to 50 per cent of this group go on to develop a mental-health problem.

But just getting the diagnosis - let alone treating its tangle of challenges - is a huge hurdle. Those with developmental disabilities may be non-verbal or have trouble communicating, so answering a doctor's questions is nearly impossible. In some cases, what may look like a symptom of mental illness is the result of an untreated medical condition, such as an impacted tooth or a gastrointestinal problem. Symptoms are often chalked up to the disability by both doctors and loved ones.

"They'll say it's because of his developmental disability that he's not interested in the world around him and prefers to sit and watch television all day," says social worker Susan Morris, clinical director of the dual diagnosis program at Toronto's Centre for Addiction and Mental Health.

Even doctors who work closely with people with autism or Down syndrome find it challenging to refract possible symptoms through the lens of mental disability. "You have to do a great deal of interpretation and extrapolation," says Vancouver child psychiatrist Vikram Dua, who specializes in treating young people with autism and mental illness.

When the clues don't click, negative behaviours may increase, and doctors may prescribe sedatives, anti-psychotic drugs and tranquillizers without any clear diagnosis. Parents and doctors think, "Well, at least he's not hitting people. We'll deal with this later," Dr. Dua says. "But it doesn't get dealt with later."

A new Canadian coalition of families and health-care providers, including Ms. Morris, has been formed to increase awareness of dual diagnosis. Since November, it's been lobbying the Mental Health Commission of Canada to address this particular intersection of mental health and disability.

"Certainly, for a long time, developmental disabilities and mental-health problems were seen to be mutually exclusive," says Krista Flint, executive director of the Canadian Down Syndrome Society. She has personally stepped in to help people with Down syndrome who struggled to receive mental health care. Still, she says that since mental illness remains stigmatized, she urges caution. For instance, as more becomes known about the high rates of Alzheimer's in those with Down syndrome, society is starting to look at every person with Down syndrome and assuming they'll get Alzheimer's, Ms. Flint says.

In the meantime, there has been some progress in finessing the medical approach to potential dual diagnosis cases. A new diagnostic tool, *Diagnostic Manual - Intellectual Disability*, was created in 2007 by the U.S. National Association for the Dually Diagnosed in association with the American Psychiatric Association. The text translates symptoms as they appear in the general population into what they might look like in people with developmental delays.

Ms. Morris says there has been some early success with the commission, especially when dual diagnosis is framed as co-morbidity, the term for having two or more simultaneous medical problems.

At CAMH's dual diagnosis clinic, which serves up to 300 patients a year, the hope is to rehabilitate patients so they can return to their families or community living.

Some provinces have created policies centred on how a dually diagnosed person should move through the system. A new version of Ontario's 1997 guidelines, co-written by the Ministry of Health and the Ministry of Community and Social Services, is set to come out possibly as early as this week to further clarify this framework.

There are many cautionary tales that highlight the risks of incomplete diagnoses.

Jill Hepburn's 28-year-old daughter has been living at CAMH for nine years (the average stay is about four months). She was 13 when she was diagnosed with her developmental disability, Prader Willi syndrome - a genetic disorder characterized by small hands and feet, abnormal growth, insatiable hunger, extreme obesity and intellectual impairment.

By then, she was into a pattern of reckless behaviour that repeatedly landed her in jail and in court. She was charged with arson after an incident while making popcorn at a group home. She was finally given a diagnosis of bipolar disorder with psychotic symptoms when she was 16, Ms. Hepburn says.

Although her daughter has had success in treatment, because of her record she has yet to find a spot in another group home. "I don't know where people like my daughter should go," Ms. Hepburn says.

In Tavish's case, he will be living with autism all his life, but his anxiety, OCD and self-harm have been brought under control with a low dose of Zoloft, an antidepressant. Without it, many of the sensory features his parents have built into their home to help him cope with his autism, including swings and a wet room where Tavish, now 7, can play with running water, might be useless. "There is no way he'd be where he is today because it would constantly be something that we were battling as opposed to something we were treating," Ms. Kliewer says.

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