

## Planning For Life After Death

*Most children with disabilities live at home.*

*What happens when they outlive their parents?*

By Susan McClelland

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Roslyn Vincent has a lot to be proud of. Thanks to her support, her daughter Beth, who has Down's syndrome, a congenital disorder characterized by slow cognitive development and a number of physical abnormalities, leads an active and independent life. Beth, 20, goes dancing, hangs out with girlfriends on weekends, goes on dates with her boyfriend, Peter, and is hoping to land a job when she finishes high school this June. It's a good life, Vincent agrees, but still she worries about what might happen if she couldn't be there for her daughter. "Will Beth go to a group home? Will everything we have worked towards disappear?" asks Vincent, 49. "The way our society treats disabilities, it's all about placement and beds. Names are never talked about and Beth, as a person, will be forgotten."

Those are not isolated concerns. There are an estimated 660,000 Canadians who have disabilities that necessitate lifelong care, and another one million with disabilities requiring periodic support, but it is parents who provide the majority of full- and part-time care. For the first time in history, most people with disabilities have lifespans equal to the general population, and since governments have cut well back on related programs and services, it raises the question: what happens when the parents die? "The demands of caregiving don't let up," says Cam Crawford, president of Toronto's Roeher Institute, a research organization promoting equality for people with disabilities. "And society hasn't developed any clear alternatives."

There are publicly funded services available. But many of those programs offer only the basics—housing and food—leaving few opportunities for social and career development. To fill those gaps, parents have to plan every aspect of their children's futures or run the risk their kids will later lead isolated lives, shunted from one impersonal public facility to another.

Case in point: care-workers in Vancouver tell of a woman with a mental disability, now in her late 30s, who while still living in her parents' home was involved in a number of outside recreational activities and led a happy social life. But her mother died before making arrangements with anyone to continue supporting her daughter, and the father was unable to chauffeur his daughter around to her various appointments. So the woman spent the next year alone in the house, isolated from the life she once enjoyed.

Making matters even worse, her father didn't make any specific provisions for her ongoing care in his will, so after he died, the woman's brother stopped supporting his sister financially and left the provincial ministry and local agencies to find her a place to live. A group home took her, but all her social networks and interests have had to be rebuilt from scratch. "I've seen a lot of people end up in lonely situations," says Al Etmanski, executive director of Vancouver's Planned Lifetime Advocacy Network (PLAN), which helps parents prepare for their children's futures, "Many parents cross their fingers, close their eyes and hope things will just work out. But there are no guarantees."

Critics blame the insufficient support systems on age-old stereotypes. “There is still an assumption that people with significant disabilities are less human than the rest of us,” says John Lord, a former professor at Dalhousie University and now a social research consultant on disability issues. It wasn’t until the latter half of the 20th century, he says, that society even considered that people with disabilities could lead productive lives. “Until recently, the focus hasn’t been on maximizing the potential of people with disabilities but on providing custodial care,” says Lord.

That outlook will have to change quickly, advocates say. By 2021, there will be 6.9 million Canadians over the age of 65, and they will be competing for the same program dollars and resources as the mentally and physically challenged. “When there isn’t enough money for services, families are used as a last resort,” says Diane Richler of the Canadian Association for Community Living. Roslyn Vincent, meanwhile, is working with PLAN, arranging for the organization to act as an advocate if her daughter needs help in her job, making decisions about health care, living arrangements or how she should spend her money. Vincent has been saving money so that Beth may someday purchase a condominium with friends and not be dependent on a group home for accommodation. That savings account is designated so that, in the event of Vincent’s death, the money will be held in a discretionary trust fund that in many provinces can be used after a parent’s death to supplement a surviving child’s employment or social assistance income.

Not all parents are in a position to do what Vincent has done. Florence Feinman, for example, who lives just outside Montreal, stayed home and looked after her three children, including Catherine, who was born with a brain injury and mild paralysis on her left side. Not working has meant that Feinman, 83, has never had many assets. She currently lives off a small, fixed monthly income, including her deceased husband’s modest pension, and 48-year-old Catherine, who lives in a group home, is completely reliant on social assistance. “I just have to trust that Catherine will never be put out in the street,” Feinman says.

Feinman’s biggest worry is that since both of Catherine’s siblings live in other cities, “if there are problems, if something changes in the staff, for instance, no one would be around to check up and do something about it.” That fear prompted Vincent (left) with Beth: ‘Will everything disappear?’