

A Mother's Hope

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Roslyn Vincent is worried about dying. It's not a preoccupation you'd expect from a healthy 50-year-old woman, but Vincent has a special reason: her 21-year-old daughter, Beth, who loves to dance and work out at the gym. Beth works part time at the local Canadian Tire store – and, oh, she has Down's syndrome. "I don't want my daughter to end up in a group home when I'm gone," says Vincent.

Maurice and Belva Baulne of Kelowna, B.C., didn't want their son to end up in a group home, either. They asphyxiated themselves and their son, Reece, age 34, in their motorhome on New Year's Eve 2001. Reece had a severe form of epilepsy and was mentally challenged. By all accounts, his private independent parents loved him, caring for him with little support from community or social agencies, but as their health deteriorated, they feared their son would end up in an institution, a fate they clearly viewed as worse than death since they chose death rather than see it happen. While Vincent doesn't agree with what they did, she feels sympathy for their struggle. "You get so tired," she says, "and you can get so isolated."

Vincent and the Baulnes are among the first wave of parents who did not routinely put their children with disabilities into institutions at birth. Thanks to advances in health care, their children are living longer and so parents are faced with the prospect that their children will outlive them, with nowhere to go except the institutions they rejected so long ago. Imagine believing that your death would mean a life sentence for your child and you get a sense of what these parents fear.

Where the Baulnes ran out of hope, Vincent and a group of like-minded parents in Ontario, British Columbia and around the world are working hard to create hope. They're part of a movement that creates communities of support around people such as Beth – people at risk of isolation because of their disorders – and they're doing it without government money. "I've seen too many programs fail because the funding gets withdrawn," says Vincent. "This program is about self-sufficiency. Money gives people like Beth power."

The program, called Planned Life-time Advocacy Network (www.plan.ca), has its roots in B.C. The idea is that vulnerable people do best when they're surrounded by those who genuinely care about them, but these caring people sometimes need support to keep the networks going. So, a paid community connector is hired to assist them and to ensure that the wishes of the person at the heart of the community are respected. Families pay a one-time fee (\$1000 in the case of Vincent's Kitchener-Waterloo, Ont. group, Planned Lifetime Networks) and then an hourly fee for the use of the connector's time (\$35 an hour in Kitchener-Waterloo). Vincent is saving now to ensure that after she dies, money will be left in trust to continue paying Beth's bills. "Even if Beth lives to be 90, it still won't cost as much as I've spent on my son, Brian's university education!" she says. (In cases where families can't afford the fees or where a person in need doesn't have family, service groups have stepped in.)

Only the community connector is paid, but this doesn't mean that the others are involved as charitable volunteers: they're friends. In Beth's case, they are people from work, school and church who have agreed to take on this special role in her life. "It's about bringing together people who share Beth's interests and who want

to spend time with her for the same reasons any of us spend time with friends, because we enjoy each other's company and have like interests." There's one crucial difference: the recognition that Beth and other vulnerable people like her need someone to watch out for them, some-one like a parent, especially when a parent can no longer be there.

Beth's network has been in place for more than a year now and Vincent is facing a new challenge. "I'll always be more involved in Beth's life than I'd be if she didn't have Down's syndrome," she says, "but her group is taking more on. I'm not as essential as I was. Eventually, she might not want or need me involved in every decision." It's a bittersweet experience that other moms expect, but one Vincent didn't think she would face: the realization that to see Beth grow means letting her go.