

Building Networks for a ‘Good Life,’ Even After the Caregiver Is Gone

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Fixes looks at solutions to social problems and why they work.

Twenty-five years ago, when Ted Kuntz, a family therapist in Vancouver, British Columbia, was preparing his will, he went around to family members and close friends asking if — in the event of his and his wife’s death — they would be willing to serve as a guardian for their son Josh, now 28, who has a severe cognitive disability and requires continual care. “Everybody said no,” recalled Kuntz. “They said the responsibility was too overwhelming, and they couldn’t imagine taking it on.”

As a young boy, Josh had frequent uncontrollable seizures. Life grew increasingly stressful, Kuntz recalled, and the family became isolated. “We were in crisis,” he said. “My wife quit her job and became a full-time caregiver for Josh. We were holding our breath constantly; people avoided us because we were angry; our family got worn out by the level of despair and pain we were feeling.”

Kuntz was fortunate, however, because Vancouver is home to one of the world’s most innovative disability support organizations: the Planned Lifetime Advocacy Network (PLAN), which helps people secure futures for family members with disabilities — not by providing them with professional services but by showing them how to build resilient and flexible networks of care: webs of personal relationships that are focused

on helping people develop their interests and abilities so they can share and enjoy them with others.

PLAN helped Kuntz prepare a long-term care plan for Josh and build up a network of support, which included other parents of children with disabilities. This is unusual. Families of people with disabilities often “exclude other people because they think it’s a burden,” explained Eddie Bartnik, the mental health commissioner of Western Australia, who has been a longtime champion for a network- and relationship-oriented model of care. “Rather than widen things, they narrow them. This creates a huge vulnerability.”

Kuntz found that people wanted to help if they knew there were others they could count on, and they wanted to hear about Josh’s life — his visits to Costco, his pleasure playing with kids, his enjoyment of a restaurant meal. “When I went back to people in my family and said, ‘This network is part of our care plan, the responsibility is shared, each of us brings a piece, you don’t have to do all of it’ — I found somebody who agreed to be Josh’s guardian.”

Today, Kuntz has taken this online, using a social-networking site called Tyze, which is designed to facilitate support networks for vulnerable people. He says the tool makes it much easier to keep friends, relatives and caregivers informed about Josh; coordinate responsibilities and roles; send messages, requests and invitations; and store care plans, financial information, advance directives and legal agreements in an online “vault,” to be accessed or shared as needed.

“My responsibility to Josh doesn’t stop when I die,” Kuntz said. “It stops when *he* dies. How can I be a responsible parent when I’m not here anymore?”

That’s a dilemma that many parents are facing around the world —

and it's one that is new. "This is the first time in history that a generation of people with disabilities are outliving their parents," observes Al Etmanski, who co-founded PLAN with his wife, Vickie Cammack. This is largely due to medical advances and improved living conditions (pdf). In the past, when people with disabilities often spent their lives in institutions, the death of a parent was a personal loss; today, for an individual with a disability who has grown up in the community, it can mean the loss of one's home, decision making power, and primary connection to the world.

Our social supports are not prepared for this challenge. With shrinking government resources, smaller families and populations growing older, it will take new approaches to ensure that people with disabilities have good lives after their parents or siblings are gone.

How do we create those models? A good place to begin is by asking a different kind of question. "The best question is not, 'What service do you need?'" says Etmanski, whose daughter, Liz, was born with Down syndrome. "But: 'What constitutes a good life?'"

And a good life, he adds, does not grow out of professional services, no matter how well designed. The hardest thing about disability is the loneliness and isolation it can bring; services do not provide love or appreciation. A good life is one in which an individual is surrounded by family and friends, is able to make a contribution and is free of poverty.

Etmanski and Cammack established PLAN in 1988, and spent years teaching others how to construct and nurture networks of care or "circles of friends," putting these principles into practice. They helped families learn to feel comfortable sharing care-giving (something that many are reluctant to do) and helped them spread roles and responsibilities, both formal and informal, across a network of friends, relatives, a network facilitator, professional caregivers and trustees. PLAN's model has spread

to 40 organizations in nine countries, reaching tens of thousands of families.

Its work has brought into stark relief the limitations of the service-oriented model. When PLAN facilitators work with families, they frequently encounter people with disabilities whose needs and deficits have been exhaustively documented, but whose interests or abilities have gone unexplored. If security and well-being come from caring relationships, as research indicates, then it follows that it's essential to find out who people are, what they care about and what they want to contribute. You can't build a good relationship exclusively around a person's needs. "There's an art in asking questions that allow a person to express themselves," explained Etmanski.

This is particularly true for a person who has had painful experiences in the social service system. That was the case with Gordon Walker, a profoundly lonely man whose six-inch-thick vocational file described him as "aggressive" and "uncooperative." When Walker first met Etmanski, he wouldn't make eye contact with him. With time, however, it was revealed that Walker loved horses; in fact, he had an unusual ability to calm them. That insight was the key to his life's transformation. Through the network, PLAN helped Walker find work in a stable — work that gave him purpose and joy for the last decade and a half of his life.

Or consider Tom, who had a cognitive disability and had been in institutional care most of his life. Tom had difficulty communicating. Through patient questioning, it came to light that his greatest wish was to live with a family. "We began to describe him not in terms of his disability, but as a 'family man,'" said Cammack. Tom was deeply religious and wanted to be active in a church community, too. "Now he lives with a family with a bunch of kids and a dog, and every Sunday he leads the processional down the aisle in an Anglican church wearing a red and white gown and carrying the cross," said Cammack. "One of the members of the

congregation says that when he sees Tom coming down the aisle, it's the most spiritual moment of his week. That's a profound contribution."

As Etmanski and Cammack saw the need for networks of care to spread more broadly, they began looking for ways to accelerate the work. There were two big needs: 1) The tools to build and manage these networks had to be brought online; that led to Tyze, a social purpose business founded by Cammack whose supporters include PLAN, the government of British Columbia, the United Kingdom department of health, Nesta and the J.W. McConnell and Robert Wood Johnson Foundations; and 2) people with disabilities and their families needed to accumulate considerably more savings to secure long-term futures. (For an idea of what it costs to care for a child with disabilities, read this powerful article by Jeff Howe, "Paying for Finn.")

Disability benefits have historically been handled like welfare, offering little incentive or scope for people to accumulate assets. Once you build up a relatively small amount of savings (it used to be \$4,000 in Canada and is still \$2,000 in the United States) you lose your eligibility for government assistance. By contrast, if you want to save for a child's education, you can open a tax-advantaged account — in Canada, a Registered Education Savings Plan, and in the United States, a 529 Plan — without such concerns.

Why can't people with disabilities or their parents do the same to ensure long-term security?

Well, in Canada, they can. It's a fundamental change. It took eight years of effort by PLAN and numerous other disability advocates, for Canada to become, in 2008, the first country in the world to enact a Registered Disability Savings Plan (R.D.S.P.). To date, R.D.S.P. accounts have been established for 75,000 people — about one-sixth of eligible individuals in Canada — who have amassed \$1 billion in savings.

What's most important is that the plan is owned by the individual beneficiaries, and they or their families and friends can contribute up to \$200,000 over a lifetime, with earnings growing tax-deferred. Add 3-to-1 matching grants, plus government bonds, and over decades, even a low-income family could accumulate \$400,000 or more; this money can be used in any way to provide security, independence and quality of life for a disabled person — without any loss of benefits. “It's a true example of government trusting individuals and families to make the best decisions without policing from the state,” says Etmanski.

In the United States, a piece of legislation with similar goals (but more modest benefits), the ABLE Act, modeled after 529 plans, was introduced this February in the Senate and House of Representatives. It enjoys broad bipartisan support — Senator Bernie Sanders, an Independent from Vermont, and Senator Marco Rubio, Republican of Florida, are both on board — and is backed by 50 national disability organizations, including the National Down Syndrome Society and the National Disability Institute.

The reason networks of care, disability savings plans and tools like Tyze — which currently has 10,000 users — are vital today is because the current system is heading for a train wreck; the looming “caregiver gap” — not just for disability — will cause suffering and dislocation for millions unless things change. Some 2.7 million Canadians over age 45 now provide 80 percent of the care for people with chronic health issues (pdf), and they are all getting older. In 1995, individuals with disabilities (including dependents and spouses) represented only 7 percent of all clients receiving British Columbia's Employment and Assistance benefits, the province's welfare program. Today, because of an aging population, greater awareness about mental health and an expanded definition of disability, they make up more than 56 percent. Similar changes are occurring in other provinces and countries.

“It doesn’t take a rocket scientist to do the demographic projections,” explains Molly Harrington, Assistant Deputy Minister in British Columbia’s Ministry of Social Development and Social Innovation. “Reconstituting the system so people can build assets has to happen or we’re going to bankrupt ourselves.”

The organizing principle of social services has to change, too, says Etmanski, with much stronger bridges between formal and informal care. “The underlying culture of the service system is still focused on the individual,” he explains. “We have to shift from a person-centric to a network-centric model — not just for disability, but for social and health services more broadly.”

Planning ahead is critical. When PLAN gives workshops to elderly parents who have children with disabilities, facilitators often ask if there’s something they could provide to help in the process. “People will often say, ‘Well, if you gave us notice that I’m going to die, that would be helpful,’” recalled Kuntz. “So we say, ‘O.K., consider this notice: you’re going to die. Let’s get to work.’”

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