

I'm 49 and have five years of freedom left. My 16-year-old is in high school and she's entitled to stay until 21 — one of the perks of having autism and being in a life skills class. Worst-case scenario: When her school days are done, my daughter could be home all day with me. Hardly a way for either one of us to have a life.

I'm not the only one dreading the future. One in five American families has a child with special needs. One in 165 kids in Canada is diagnosed with an autism spectrum disorder. And while the government finally understands that early support and treatment are key, officials seem to forget that these kids grow up.

My rapidly sprouting teen craves her own space. Sometimes she refuses yet another "life skills building" outing like grocery shopping, saying, "I want to chill, Mom." She retreats to the basement to watch TV (*Crash Test Mommy* and *Birth Stories* are current faves) and to cruise on Facebook. Lately when I kiss Talia goodnight, she says the eeriest thing: "Mom, you're the only one who can protect a child." While I suspect she's echoing a line from a diaper commercial, it haunts me still.

I call a case manager (I've become a case!) asking for the blunt truth about our future prospects. Two words sum it up: waiting lists. Residential spots don't come up often. I hear about a single mom whose son finished school and awaits a day program. To keep her job, she's hired a neighbour to check on her son a few times a day. This is my worst nightmare.

I email my disability networks to unearth women in the adult parenting trenches. Responses flood in. It's rare for a "special-needs mom" to be asked about her own quality of life. Fifty-nine-year-old Lyn Kyneston of Pickering, Ont., says, "We had expected our son [28 with autism] would be on his own with supports. Individual funding is not available, so he remains with us — probably until one of us dies or we're in crisis. We have limited time to ourselves and never any time away. We worry constantly about what will happen to him when we're gone."

Joanna Bullard of Windsor, Ont., is a 60-year-old single mom to a 30-year-old autistic son. She warns, "When the kids 'graduate,' there is nothing but endless applications for funding. I can't afford to retire. I have no savings. I'll retire when I drop dead."

Not the hope I was looking for. Ironically, as I research this story, my father and my mother-in-law both fall seriously ill. For weeks I battle highway traffic en route to hospitals in two different cities, pickle my hands in visitor sanitizer and jot down medical updates. I'm the poster woman for the sandwich generation of caregivers. I need ideas for the future so I can cope with today. I need a mentor.

Enter Linda McCullough, a 53-year-old divorced mom in Kincardine, Ont. "When my daughter Jen was in high school, I never dreamed she'd ever live on her own," she says. When Jen was in her twenties, she was offered a spot in a supported living apartment. The hitch? Her roomie would have been a guy. So McCullough and Jen joined forces with another family to create Plan B. Now 27, Jen shares a townhouse and daily life with her good friend Rosie. While both contribute to living expenses, Jen pays rent to Rosie's parents who bought the house in trust for their daughter. Rosie is more independent but has some physical limitations, so she handles tasks such as writing shopping lists while Jen tackles housecleaning.

Here's where the inspiring part comes in. I assumed that Jen must have skills far beyond that of my daughter, but that's not the case. Although bubbly and outgoing, Jen also has a developmental disability and limited speech (like a two-year-old). Since she's mystified by the concept of time, she uses alarms to remind her to brush her teeth or get ready for the taxi. With some ingenious problem solving, McCullough and Jen are making it work.

"I have a little more freedom now," McCullough says, although she still sees or phones Jen with reminders most days. And every other Saturday, she picks up her daughter to live at home for the weekend when they shop for the week's food, mostly frozen dinners to reheat. Cooking's still a bit iffy — unless Rosie's also home for dinner. "Jen has already set two microwaves on fire when she was alone," her mom explains. In reality, McCullough does the job of a support worker, along with her ex-husband, Chris, who spends every second weekend with Jen.

But now she's got a new love in her life. Just as Jen moved out, McCullough met her boyfriend, Keith, a photographer. Next summer, they're hightailing it to Nova Scotia — her first vacation ever without Jen. And Jen has travel plans of her own — an escorted trip to Niagara Falls, Ont. To help her earn travel funds, Keith

gave Jen a part-time job shredding paper at his studio. Eventually, McCullough wants to reduce her hands-on help with her daughter. “By the time I’m 60, I’m hoping she’ll be set. I’m seeing such leaps in maturity.” And after years working full-time as a shipper/receiver, McCullough dreams of cutting back to make time for her real passion — sewing. “I want something for me.”

Okay — I’m feeling more optimistic. If McCullough and Jen can pave the way to independence, we can too. Talia can read and type, speak clearly and tell the time. We’re well connected in our community. Maybe Talia’s already met her future housemate. I realize I’ve got to stop doing so much for her. The next day, I go on breakfast-duty strike and show Talia how to toast her own cinnamon bagel.

I troll further for mentors and find Martha Eelen, a Toronto-based artist and single mom to 31-year-old Gabe, who can never be left alone. Eelen says Gabe is legally blind, uses a wheelchair, has epilepsy and is considered mentally challenged. “But he’s smart in some ways. He has many interests.” For years, Eelen’s life was consumed with parenting Gabe, coping with welfare living and “strenuously” lobbying the government for individualized funding — money attached to a person instead of a program. “I didn’t want a group home for him; I wanted him to live in the same world as me.”

Finally, at 52, Eelen has secured funding for Gabe that allows her to flourish as a professional artist and part-time instructor at the Toronto School of Art. And each day, Gabe explores his passions such as riding the subway with support workers. But Eelen admits organizing Gabe’s life is another full-time job, involving hiring, training and supervising seven or eight support workers. “It’s like being an unpaid manager of a business.”

Multi-talented, Eelen has also created a niche doing freelance home repairs. Recently, she constructed a unique way of living with her son. By installing an extra door in their house, she created her own entrance and two separate living spaces. “Gabe considers this his own apartment and loves it. I’m getting a taste of a different kind of relationship with him.” And for the first time, Eelen has a private space to relax. When a worker is there, she can shut the door, brew tea on her hot plate and read on her own couch.

That time is precious. Some nights and weekends, Eelen opens the door and takes her “shift” supervising her son, sometimes involving all-nighters in the ER

dealing with Gabe's seizures. And she's perpetually on call. "I always have curfew — 5 or 11 p.m. I need out of that."

She's getting there. By extreme planning a year in advance, Eleen "sinks her teeth" into painting at artist residencies — most recently in the Arctic. "I got a glimpse of what it would be like to have that autonomy all the time. I felt back in my skin."

She paints a picture of their future: "We're both ready for more freedom. I'm bracing myself to lobby the government again, because 31 years as a caregiver is enough for me." She plans to meet with Gabe's informal microboard (see "Where to turn"), a support circle consisting of a volunteer advocate, Eleen's mom, and close friends. "[A formal] microboard will do what I've been doing — advocacy, payroll, day-to-day organizing. I'd like this in place before I die so that I can rest easy that this will go on and Gabe won't end up in an institution.

"We've been through so much together," she says. "Our relationship deepens all the time. He's so vulnerable, and I've stood by him and it's brought me into my humanity." With her artist's eloquence, Eleen sums up what I've heard from so many women: Our kids transform our lives profoundly. How can we do the best for them without disappearing ourselves?

Just when I doubt if I'd have the stamina of either McCullough or Eleen, I hear another story from my own community of Guelph, Ont. Jennifer MacKenzie's 24-year-old son, Alec, shares a rented house with two other men with developmental disabilities. Community Living workers provide support from 4 p.m. to 10 p.m. on weekdays, and 10 a.m. to 10 p.m. on weekends, a flexible model of staffing that I hadn't heard about before in my community.

"We expected that Alec would be living with us until he was 30 or 40 years old," MacKenzie says. "He's very content now and loves the freedom as any twentysomething would." She was thrilled when Alec visited sporting a new haircut. "It was the first haircut of his life that neither his dad nor I was not a part of! It's amazing that I can go three or four days without talking to or about him with some sort of professional. Even more amazing is that I don't worry about him [much]." Instead, she enjoys seeing Alec when he returns home for weekly

dinners and holidays. When not working as an educational assistant, 51-year-old MacKenzie travels, enjoys a social life and spends more time with her other kids.

But this success story was hard won. MacKenzie and her husband weathered two “stress filled” years when Alec lived in an apartment program with inadequate support and an incompatible roommate. Her advice: “If the family and the individual want independent living, be willing to take a risk and work toward a solution together with agency support. This means you’ll be relinquishing some control as well.”

That’s the key — finding balance between surrendering control and fighting for change. Slowly the system is evolving so that families can piece together a good life. Besides, who knows how much Talia will change in the next few years? As my mentors stress, I need to start by letting my daughter do her own dreaming. The more she can plan her own life, the happier she’ll be. And the more comfortable I’ll feel letting go.

Time to start.

“Talia, what do you want to do when you grow up?”

“Don’t know.”

“Would you want your own apartment?”

“Yes — with a roommate.” Pause. “Awwww, Mom — I’m not moving out right now. Hmm, could my dog come with me?”

She springs off the couch, runs down the stairs and turns on the computer.

Conversation to be continued. We’ve got five years.

Canadian Association for Community Living

This [association](#) provides information, support and advocacy for people with an intellectual disability and their families.

Ontario Adult Autism Research and Support Network

This [website](#) includes worldwide research, events and innovative solutions. Follow the links to sign up for the electronic mailing list.

PLAN

This non-profit [organization](#) helps members with future planning and creating support networks.

Vela Microboard Association

This [association](#) provides information on creating a microboard — a non-profit organization including the person with a disability, family and community.

More Than a Mom — Living a Full and Balanced Life When Your Child Has Special Needs by Amy Baskin and Heather Fawcett (morethanamom.net)

Advice from parents who have been there

“With your child, dream big. And do the same dreaming for yourself. Don’t compromise.” – Martha Eleen

“Ensure that there is a circle of people around your child, who will spend time being with her. Involve your child in decision-making about her future. Keep probing to find out what she wants versus what you think she wants.” – Lyn Kyneston

“Apply for individualized funding well before you need it.” – Joanna Bullard

“Teach your child as many life skills as you can. Check out respite options [programs providing overnight, weekend or longer care], so he can get used to spending time away from you. Learn to let go.” – Deb Lajoie , 53, of Trenton, Ont., mom to a 30-year-old son with special needs who now lives in his own apartment

“If you have a teen, look into options now. Contact your local Community Living Network with families and search for individuals who are compatible with your child.” – Linda McCullough

“Talk to other families who have children older than yours. Advocate as a collective group. Don’t take no for an answer — keep working at it and find other solutions. Be forward thinking but also appreciate the moment. Remember to take care of yourself.” –parents of teens and adults in the Dual Diagnosis Program at the Centre for Addiction and Mental Health, Toronto

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