**A keeper from Day 1: Two decades on**

*My child with Down syndrome faces the extinction of her kind and that's breaking my heart,****Ann Auld****writes.*

**Within** moments of her birth, the doctor said, "She's perfect."

**Within** hours of her birth, a nurse said, "Put **that Mongoloid (**metaphor) in an institution; she'll be too much for you."

**Within** days of her birth, the specialist said, "She'll be trainable."

**Within** months of her birth, the spouse said, "I'm having a vasectomy."

**Within** years of her birth, the psychologist said, "She's functioning at the level of a 2 1/2-year-old."

**Within** 10 years of her birth, the families who had been **travelling this journey** (metaphor) for many years said, "Once the cute factor wears off, you're on your own."

**Within** 20 years of her birth, the government said, "With the wait lists and no money, don't expect any services."

And here we are now, my daughter and me, an **A-to-Z of need (**metaphor).

She is a fatherless adult **who can charm with the best of them, yet cannot cross a street by herself. She's a person who knows all the Top 40 pop tunes from every online source and who wants to compete on *The Voice*, yet, cannot sing a note**. (contrast)

I am a graduate in writing creative non-fiction who keeps up the pretense of operating an academic tutoring service for forever learners; a woman with **aging, inflamed joints** (imagery) who **carries enough worry to fill up a universe (hyperbole).**

*(Anecdote) Almost 20 years ago, I wrote " [A keeper from Day 1](https://www.theglobeandmail.com/life/facts-and-arguments/from-the-archives-a-keeper-from-day-one/article31205652/)" for Facts & Arguments about my daughter, who has Down syndrome. There was a text box in the upper lefthand corner of the page that proclaimed: "Every weekday, one million Canadians read The Globe and Mail." Yet, the only written response I received, in the following week's paper, came from a fellow who preached about "this chosen child," and offered up a herbal concoction that could "cure" her. The illustration that accompanied my piece,* ***with the baby in utero surrounded by a flowering, thorny rose bush( imagery)****, hinted at what could be ahead.*

*I opened my piece with a question: "Do you want a boy or a girl?" I had wanted a healthy baby, the sex was unimportant.*

When I wrote the piece, my baby was 10 months old and so much had happened already. She'd had life-saving surgery to correct an abdominal condition more prevalent in infants with Down syndrome. She had learned how to nurse and to feed from an adapted sippy cup. She had learned how to sit up and to begin vocalizing her wants and needs.

I had learned how **to navigate (**metaphor), not always successfully, all of the major institutions: medical, educational, legal, fiscal.

I wondered about her heart's strength, as babies with Down syndrome often have significant cardiac problems. Now, I look for heart shapes everywhere and post photos of them online as a way of superstitiously warding off death and medical problems.

My daughter, meanwhile, has not only learned how to walk, but also to talk and to advocate for herself with help. She has graduated from high school. She has won so many awards I don't know where to display them in the house.

And, here's the thing: **She is a keeper** (metaphor). With the paltry amount she receives from the government, she cannot afford to leave **the nest (**metaphor), even if she were capable of making those kinds of decisions.

While her peers announced at commencement that they were heading off to university, to travel or to work to earn enough to travel or attend university, my girl simply stated that school had been "amazing and magical."

There are few plans for the future, other than a dim hope of continuing to have a good time, surrounded by friends. **Not so atypical, after all (irony).**

What is atypical is that I, her **aging solo mama (word choice)**, will carry on indefinitely as her unacknowledged, unpaid caregiver. Don't get me wrong: I am very skilled at this task, having been involved in it for more than three decades.

Of the numerous lessons I have learned, the one I never figured out is that I would be raising an **endangered species.** Yes, that's right: an endangered species. As one of a group of humans who are actively discouraged from reproducing, chances are that my "keeper" will go extinct in a few decades. A few countries are already enacting game plans, including genetic testing and termination that discourage women from ever bearing those deemed "different."

Back in 1997, I wrote: "I dwell at length on the **what-ifs** (word choice). If I had had amniocentesis at 16 weeks, would I have continued the pregnancy knowing what was to come?" So I, too, contributed to the notion that being different is somehow wrong, not okay, not acceptable.

But I also wrote: "What I have learned is that intelligence is as variable and unique as our baby's extra chromosome."

In a few months, my keeper may receive a **few crumbs of support** (metaphor) that will cost her entire **paltry** monthly government "pension" to put it into programs.

In a few weeks, she will attend a weeklong camp for other young adults who live for the joy they bring to others.

In a few days, she will receive yet another award for service to her community.

Within a few hours, she will celebrate having survived another day.

Within a few moments, she will break my heart and **patch it back up again (**metaphor).

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<https://beta.theglobeandmail.com/life/facts-and-arguments/most-popular-personal-essays-of-past-year/article35623742/?ref=http://www.theglobeandmail.com&>