Opinion | As disabled people increasingly outlive their parents, many siblings struggle to take on new care responsibilities

Jan. 19, 2026 2 min read (7)

“Siblings are the second-longest care providers for people with disabilities after parents, however, they are often ineligible for many caregiving benefits, tax credits and supports typically accessed by parents,” write Pamela Block, Helen Ries and Dima Kassem.

Dreamstime

By Pamela Block, Helen Ries and Dima Kassem Contributors
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Canadians who are autistic or who have intellectual disability are living longer, reflecting significant medical progress and a decline in institutionalization, which shortened peoples’ lives.

This growing longevity also brings new considerations for families. Many disabled people are now outliving their parents, leaving siblings to step into the care role.

Most siblings are unprepared for this life-changing transition and lack the necessary support and resources to succeed. We need a societal shift in how we view this care relationship so both disabled people and their siblings, can live in dignity and security in their later years and as family roles evolve.

Our new study examined the relationship between disabled people and their siblings during times of major life-changing transitions, including when parents can no longer provide care due to illness or death.

Interviews with 52 disabled people and siblings in Canada revealed a consistent message: the lack of resources and support left them feeling unprepared and under significant stress as they adjusted to their new responsibilities.

Siblings are the second-longest care providers for people with disabilities after parents, however, they are often ineligible for many caregiving benefits, tax credits and supports typically accessed by parents.

Canada’s broader disability support systems for disabled people are woefully lacking and lagging behind other countries particularly in supportive housing, where decades-long wait-lists can push disabled people toward inappropriate or unsafe living situations including long-term institutional care or even choosing medical assistance in dying (MAID).

Rather than providing a strong, social safety net, governments have increasingly shifted the responsibility for care onto families. When parents can no longer provide support, that responsibility falls to siblings, who may themselves be managing careers, raising children, or dealing with their own health challenges.

Not only must governments improve disability support and provide the resources to help families build robust support networks, but parents of people with disabilities need to shift their mindset.

Too often there are sweeping expectations about siblings automatically stepping in when parents can no longer provide care — making assumptions without discussing what support is reasonable to expect.

In many families, siblings are left out of critical discussions about care or future planning. In some cases, parents fail to do any future planning to save enough money to provide the right support after they are gone.

Others assume they know how the future will unfold and lock down their estates leaving siblings with little flexibility to deal with unpredictable events like regressive policy changes, pandemics, or the aging process.

Instead, parents should include siblings early in future care planning. They must listen to and respect their wishes, including their stated capacity to provide care and the need for them to have flexibility to adapt to unforeseen future circumstances.

Without adequate supports, disabled people risk being overlooked or neglected if their siblings are unprepared, unable or unwilling to step in.

Losing a parent is traumatic for anyone, but the consequences of the loss are that much greater for siblings.

Intertwined with feeling grief, one or both siblings may also be under severe stress as they face significant upheaval — including possibly having to relocate and leave behind their home, careers and social routines. Some also feel uncertainty when making care decisions — feeling the weight of parental expectations beyond the grave.

In our study we found that to cope, disabled and nondisabled siblings use strategies like “world-making” — a process in which siblings together co-create a new vision for their lives together. This creative collaboration can foster mutual support and help siblings adjust to their new reality and comfort each other.

But resilience alone is not enough.

Siblings play a vital role in ensuring that disabled people live in dignity after their parents are gone. It is time for systems and our society to recognize that role and provide the resources and supports they need to succeed.

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