

# SPEAKING UP for those who can't

Aging parents of developmentally disabled need support | by Jennifer Walker

All parents worry about their children. But at some point, your child grows up, matures and moves away from home, and you begin to relax. Sure, you'll always worry a little bit but, for the most part, the tough years are behind you and it's time to enjoy some newfound freedom – and maybe a grandkid or two.

For those seniors who are raising adult children with a developmental disability, the worry doesn't abate. The issues and concerns these people face are numerous and unique. "I remember saying to David, 'If some morning you can't wake me up, you go and get the neighbours,'" explains Julie, 81, the mother of 51-year-old David, who has autism and a developmental delay. "He just said, 'Well, Mom, if that happens, I'll just get ready for work.' That's when I realized that if anything happened

to me, he wouldn't be able to handle it."

And Julie is one of the lucky ones. By showing foresight 20 years ago, she managed to find a good facility that would take David. And this planning paid off last year. When Julie underwent hip replacement and surgery to repair a broken pelvis, David was already established and happy in his home at L'Arche Hamilton.

"When I was in the hospital, I didn't have to worry about him at all," she says. "The people at L'Arche brought him every week to visit me and when I got home to recuperate, they brought him to the house to visit me because I don't drive anymore."

It's that kind of peace of mind that every Canadian with a child who has a developmental disability should be able to expect. But many parents who have been raising their developmentally delayed chil-

dren aren't prepared for the day when, because of sickness or death, they can no longer provide care. Finding a home that will offer a suitable level of care for their child is very challenging.

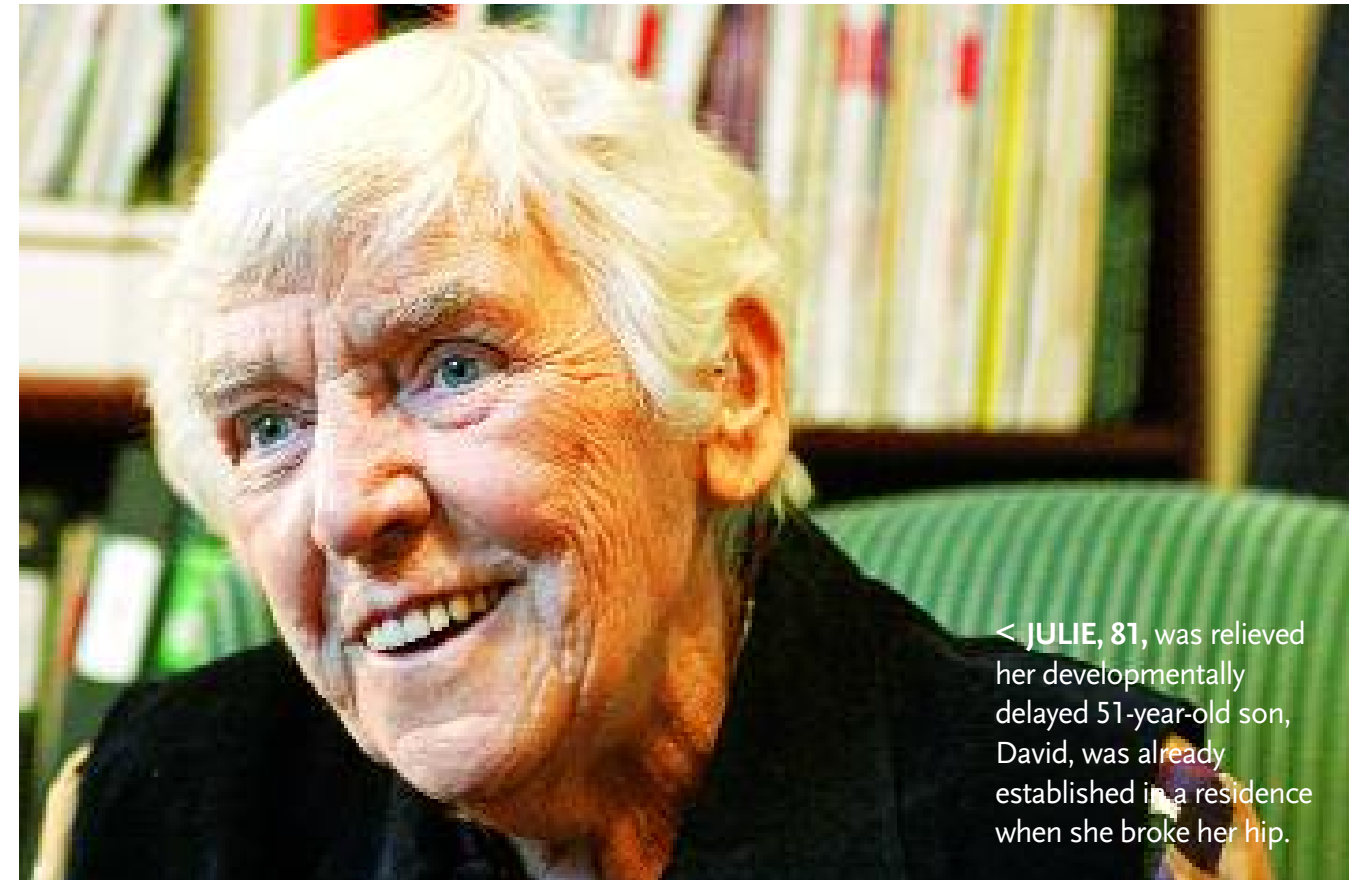
"Raising children at home who have disabilities is a great challenge," says CARP's Bill Gleberzon, co-director of government and media relations. "And as both parents and children age, this challenge intensifies. CARP believes that these parents and children need the maximum support from governments to help them in every way."

Unfortunately, this support is dwindling. In 1996, governments began closing institutions that had housed the developmentally disabled since the 1960s. The plan was to integrate them into communities. But the resources and facilities needed to accommodate this plan haven't kept pace with client need.

Moreover, unlike a nursing home, which has a fairly regular turnover of clients, developmentally challenged people needing residential care may move in at the age of 20 and stay there for decades. With the closing of institutions, the demand for these residences is even greater.

And waiting lists for such facilities are long and, unlike nursing homes wait lists, once your name comes up, you go where there is a space. There is no choice. For those which children who have a dual diagnosis requiring specialized care, this can

Photography: Karen Roberts



< JULIE, 81, was relieved her developmentally delayed 51-year-old son, David, was already established in a residence when she broke her hip.



< DR. JANE MORGAN is one of only a few doctors qualified to treat patients who are dually diagnosed. At least 96,000 Canadians have both a development disability and a mental illness.

be a monumental cause for concern.

"[Dually diagnosed] people have a developmental delay and a psychiatric disorder," explains Dr. Jane Morgan, a medical doctor and child psychiatrist in Ancaster, Ont., and one of the few health-care professionals who specialize in treating both disorders. "They develop depression, psychosis, anxiety disorders just like those in the general population, but they also have a developmental delay."

The Canadian Mental Health Association estimates that one per cent of the Canadian population, or about 320,000 people, has a moderate to severe developmental disability and of those, at least 30 per cent, or 96,000, also have a mental illness. But the numbers could be as high as 50 to 60 per cent.

Mental illness can be treated, but many

people aren't diagnosed for years, if at all. "I've treated many people who have been ill for 20 or 30 years and have gone undiagnosed until now," says Morgan. "People assume the behaviour is part of their delay. And if someone has been placed in an institution since childhood, there isn't really anyone to take an interest in them."

Compounding matters is that it's even harder to find a facility for those dually diagnosed. Their condition falls under two separate government umbrellas that don't currently cross over. Developmental delays are covered by the Ministry of Community and Social Services; mental illness is covered by the Ministry of Health.

"What happens is if you start a group home to accommodate someone with dual diagnosis, you probably wouldn't get the funding for them because the mental ill-

ness falls under the ministry of health and the developmental delay falls under the ministry of community and social services," says an employee of a residence for the developmentally challenged in Ontario who requested anonymity. "These are the people falling right between the cracks because the government says you have to be under the umbrella of one or the other but you can't be under both."

So what do those who slip between the cracks do? Many have no choice but return home to live with parents they haven't lived with for 20 or 30 years. Their parents have aged and may no longer have the physical capabilities of providing care. Or they may still be working, and one parent will have to stay home because the adult child who has lived in an institution requires constant supervision.

Even if both parents are home to care for their adult child, it takes a huge toll emotionally and physically. And there is always the financial cost to consider, whether it's paying for psychiatric treatment, community programs or finding some sort of respite care for those much-needed stress-relieving breaks.

"Parents don't feel comfortable leaving their adult child with someone but it's also limited as to who can do that kind of care," says Morgan. "And who's going to pay for it? You are now talking about a group of people who are living on pensions."

Parents who want to find quality care for their adult child with dual diagnosis need to consider what the residence has to offer. Psychiatric treatment can really improve the quality of life for those with dual diagnosis, even allowing them to live independently with supervision, making regular behavioural therapy sessions a critical part of treatment. Many developmentally delayed adults, including those with dual diagnosis, want to and can work.

Morgan does cognitive behavioural therapies that focus on making the person more independent so they can eventually be placed in either a residential or a day program. "I have a client in her 40s with Down's syndrome and she couldn't touch paper, which meant she couldn't go to the bathroom on her own. So she couldn't be independent enough to get into a program," explains Morgan. "We have practised many ways for her to touch paper so she can now be independent enough to get into a program."

But the type of therapy that Morgan specializes in is scarce, and there needs to be more trained specialists who can help give these individuals the therapy they need to lead more independent lives, alleviating the burden on their aging parents.

The reality is that people with developmental delays are living longer now. We are going to be seeing many more seniors

### CARP RECOMMENDS

Older parents raising developmentally delayed children need:

- Adequate respite for parents or other family caregivers.
- More group homes and community-based day programs with programs for those with multiple challenges (e.g. mental and physical disabilities).
- Increased transportation not limited to specific boundaries.
- System of funding to serve specific needs of individuals with disabilities.
- Adequate compensation for family caregivers.
- Regulated facilities for those who can't stay at home.

with developmental delays. "I have friends who say, 'I pray my child will go before I do' because they just don't know how their child will manage without them," says Julie. It's an issue many face if they don't place their child in an appropriate facility or arrange care for them before they die.

While the issues for those with developmental disabilities or those caring for them may not directly affect all Canadians, these people need strong advocates. They don't have advocacy skills of their own and once their parents or family are gone, they must rely solely on society to protect them. That's why funding quality care is crucial. In recent years, the government has promised more money for families with developmentally challenged children but we need to ensure that the money gets to where it needs to go.

What can we do? "Contact your repre-

sentative in parliament and express your concern and give a voice to these people," says Morgan. "There needs to be better communication between the health and social services ministries. There needs to be more bridging between these groups so that peoples' needs can be met."

And we need more money spent on community services for people who can live independently with supervision and many more safe residences for people who need constant supervision – especially for those with dual diagnosis who require regular psychiatric treatment.

"When you make the decision for your child, it's harder than if they made it themselves because you want to be sure it's the right one," says Julie. "Before it was difficult because I worried 24 hours a day that David wouldn't be taken care of if something happened to me. I love him way too much to ever let that happen to him." ●

### RESOURCES

**L'Arche Canada**  
514-844-1661 [www.larche.ca/en/](http://www.larche.ca/en/)

**Canadian Association for Community Living**  
416-661-9611 [www.cacl.ca](http://www.cacl.ca)

**Canadian Mental Health Association**  
416-484-7750 [www.cmha.ca](http://www.cmha.ca)

**Planned Lifetime Advocacy Network (PLAN)** *Helps families secure a future for a child with a disability.* 604-439-9566 [www.plan.ca](http://www.plan.ca)