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A past enveloped in love, a future that's uncertain

By Maureen O'Hagan
Seattle Times staff reporter

James Jensen considers himself a "ladies' man," even though he's never been on a date.

He likes to say he's "retired," although he's never had a serious job. When a cashier asks for money, he responds, "You'll have to talk to my banker."

The banker in question is his mother, Delores Jensen, who's been his staunchest defender, his biggest fan and his loving caregiver for 47 years. And James, if it isn't clear by now, is a charmer.

He was diagnosed at birth with Down syndrome, a chromosomal disorder marked by impairments both physical and mental. James can handle some daily tasks alone, such as dressing and setting the table, but he can't count money or operate the oven or clearly articulate when something's wrong.

He's never lived on his own and doesn't want to. He enjoys the companionship and security provided by his parents in their Enumclaw home.

Thing is, Delores is 81; James' father, Allen, is 82, and over the past few years they've begun to show their age.

James probably has many years left. In fact, he is part of the first generation of people with developmental disabilities likely to outlive their parents in great numbers — a situation that, years ago, few would have predicted. State officials say 8,200 people older than age 40 are on the rolls of the Division of Developmental Disabilities. Experts say thousands more may be eligible.

Those numbers will only grow as baby boomers with disabilities continue to age.

Meanwhile, most caregivers are relatives, whose dedication saves the state untold millions.

Put these facts together and big questions loom: What happens when people like the Jensens can't do it any longer? And who's going to pay for it?

James and many thousands of others will need places to live, along with additional services and caregivers when their parents are gone. They're also likely to need extra help because they often show early signs of aging.



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Delores Jensen, 81, says her son, James, has been a blessing. When James was born in 1961, most children with Down syndrome were institutionalized. But the Jensens refused to let that happen. "He's been such a joy in our lives," Delores says. "I don't know what we'd do without him."



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James has won over many a stranger with his warmth and smile. "He's always been well-adjusted," his mother says. "Very loving and outgoing."



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James celebrates his 47th birthday with friends and family. At left is Emily, one of Mary Baker's three daughters. "They call me uncle," he says proudly.

That's becoming increasingly evident with James, as the abilities he once had are starting to fade.

Sustained by faith

The Jensens are a family that runs on the twin engines of faith and routine. Lunch is at noon sharp, on account of Allen's diabetes. James gets ice cream before bed every night. Medications — a few dozen among the three of them — are organized on Fridays; church is first thing Sunday morning.

Yet from James' birth in South Dakota, the family has been on the cutting edge of what some call a great civil-rights movement — the struggle, successful in many ways, by people with disabilities to be treated like everyone else. They joined that movement the day James was born, in March 1961.

One look at him and doctors knew he had Down syndrome. Before Delores could see her new son, a nurse whisked him away.

At that time, many kids born with Down's and other developmental or physical disabilities went straight from the hospital to an institution. "Just forget about him," parents were sometimes told. "Tell people he died."

Delores recalled: "One of the sisters came in and said, 'You don't want to take this child home.' "

Without thinking twice, she snapped, "I am not going to let you take this child."

For two months, James remained in the hospital, small enough to fit in the palm of Allen's hand, taking food through a tube until he was finally able to swallow. When doctors sent him home, they warned he might never learn to walk.

At that time, there were few programs the Jensens could turn to for help. Outright discrimination was everywhere. In fact, until the mid-1970s, some school districts, including Seattle, refused to accept many kids like James. Parents were told "retarded" kids couldn't learn, anyway. They certainly didn't belong with "normal" children.

The Jensen family, which also included daughter Linda, who is 12 years older than James, was pretty much left to figure things out for itself.

"We knew the Lord was going to tell us what to do and how far to go," Delores said.

Progress, and problems

In 1964, Allen got a job as a school-bus mechanic in Auburn and they moved west, leaving a close extended family behind.

Delores remembers crying those first months, holding James close and watching as the rain came down in a dull and endless gray. She was so very lonely. James was her comfort.

Luckily, they landed somewhere with a school that didn't exclude kids with disabilities. From first grade until graduation at 21, James attended the Grandview School in Kent, a newfangled — and now defunct — program that served special-education



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James, left, and his father, Allen, 82, in their Enumclaw home. James enjoys helping out with chores even as he's showing signs of early Alzheimer's. "Some days he's very quiet," his mother says. "Things like setting the table he doesn't always do right anymore."



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After Mary's brother died 22 years ago, James knew what she needed. "I'll be your brother," he said at the time.



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As Delores and Allen leave James' birthday party, Delores embraces Mary. "I don't know how we got to be blessed so much with that girl," Delores says.

kids from area districts.

The world learned along with the Jensens. Today, institutionalizing kids is rare. Although discrimination exists, people with developmental disabilities go to school and play sports and work like everyone else.

That's the good news. But along with the progress came new hurdles. Because institutions are no longer in favor, and because other housing options have limitations, about two-thirds of people with developmental disabilities live with parents or siblings, according to national experts. That has made parents the default long-term-care system, according to Linda Rolfe, head of the state Division of Developmental Disabilities.

"Most of us who have kids, we sort of launch them at some point in their lives," said Matthew Janicki, a researcher at the University of Illinois, Chicago, who studies aging and disabilities. Parents of children with disabilities, however, "stay with them for their lifetimes. We're talking about 40, 50 years of caregiving."

It is a strain on many families, but for a long time, that arrangement worked because the parents outlived the disabled child. But nowadays, people with Down syndrome often live into their 60s. People with other developmental disabilities live just about as long as everyone else, thanks, in part, to medical advances.

Some have jobs and will manage when their parents pass away. But for the rest, the future is uncertain.

A second family

The Jensens don't rely heavily on state services. Instead, they have family friend Mary Baker.

They tell the story of their meeting over and over.

James was around 8. His best buddy, Mike, who also had Down syndrome, had taken his little sister Mary to a Grandview dance. James approached Mary, then around 6, and bowed.

"Do you remember what you said, James?" Mary asked recently.

James smiled, but his face was blank. He couldn't quite remember.

"May I ... ," Mary prompted. Nothing.

"May I have ... ," she tried again.

"May I have this dance?" James said tentatively.

On that dance floor, he won Mary over. As the years have gone by, Mary has come to consider the Jensens a second family.

"She couldn't have been any closer to us had I borne her," Delores said.

"Anything for Mary," Allen said, beaming.

Mike died years ago of cancer, but the families remain close. Once a



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"I know I'm overly protective and always will be," Delores says. Here, she tucks James into bed. "She does just about everything," her husband, Allen, says.



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Delores holds a picture of her and James when he was about 2 years old. "And look at me now!" he says, as Delores flips through family photos.



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Delores prays before dinner. "A lot of people don't realize what people in our situation go through," she says.



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Over the past year, James has gone through spates of feeling down. "I love him like a brother," Mary says, "like a

month, James spends the night with Mary and her family in Puyallup. Allen acted as chauffeur the day Mary married Bruce Baker. And now Bruce and Mary's three daughters are part of the Jensen family, too.

"They call me uncle," James said proudly.

He likes the sound of it so much he repeats it: "They call me uncle."

In the next half-hour, he says it again and again. To the Jensens, it is a sign their son has changed. There is the James of today — repeating himself, getting confused — and the James who once was.

A change in James

The old James used to talk about the school dance all the time, acting it out and relishing every detail. He used to have beautiful penmanship. He used to love to go bowling or to the movies with friends he made through a parks department program. He used to be so happy-go-lucky.

Now he gets moody. He mopes around and says he just doesn't feel like going to the movies. He can barely write his name anymore. He sometimes gets halfway through setting the table and just stops.

He's clingy. Needy.

Delores whispers: *Alzheimer's*. Like many middle-aged people with Down syndrome, James is showing signs of early aging, including dementia. People with Down's also tend to develop early arthritis, prostate troubles and hearing loss. Other developmental disabilities come with their own ills: People with cerebral palsy often develop joint problems or chronic pain. Autism is associated with digestive disorders. Seizure medications can lead to osteoporosis.

For James, the dementia symptoms come and go. Every so often, the old James is back, smiling and joking, eager to vacuum, fold the laundry and do other tasks. "That's my job," he likes to say.

But Delores is afraid to leave him alone because he might wander. She helps him shower because he doesn't always remember what to do. She reminds him to use the bathroom.

"When he gets more involved and is more dependent on physical care, it's going to be harder and harder for them," said Janicki, the researcher.

James also has acid-reflux disease and ill-fitting dentures. He has arthritis in his hands. Then there's the prostate trouble that began a few months ago. Doctors were lucky to discover it, given that James couldn't describe what was wrong. He just told his parents he didn't feel well.

"She does just about everything," Allen said of his wife. "Brushes his teeth, makes sure his clothes are washed. Gives him his money and counts his money when he gets it back [from the movies]. Makes all the doctor's appointments and takes him."

At night, he added, "Jim has just got to moan a little bit and she's up like a shot to check on him."

Sometimes it's two, three, four times a night.

"I just sit there in his chair next to him," Delores said. "Sometimes he wants you to stay with him until he goes back to sleep."

Delores also takes care of Allen. Years ago, he loved tinkering with old cars. But he's become frail. He's survived cancer and heart surgery and now hobbles around with a cane. He has no feeling below the knees.

"I never leave the two of them alone except for Bible study once a month from 9 to noon," Delores said. "That's my only activity — that and going to get my hair done."

Since James was born, Delores and Allen have gone on a trip alone only once: for a weeklong cruise to celebrate their 50th

child. I would never let anything happen to him."

A lifetime of care

People with developmental disabilities are beginning to outlive loved ones who have tended to them. That presents difficult choices for families, friends and society — and the prospect of a wrenching change for James Jensen.

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wedding anniversary in 1997.

They will never say James is a burden; he is a blessing. It has something to do with David, their first son, who died at age 3. "I think that God knew we needed someone to enjoy in our old age who would be with us and who loves unconditionally," Delores said.

"And he certainly does."

Uncertain future

Mary calls herself a planner. So she's been thinking a lot lately about what will happen when Delores slows down.

"She's the glue that keeps that family together," Mary said.

It's not hard to imagine the next step — for James and thousands of others like him.

"We're starting to hear about them now," said Kathleen Watson, who specializes in elder issues at the University of Washington's Center on Human Development and Disability. "Suddenly, this person is on the doorstep of the system. We expect that's going to be happening more and more."

The state might place someone like James in an adult family home, which costs an average of \$75 a day. People who need more care might go into one of the state institutions, which can cost more than \$500 a day.

Such costs haven't been built into the state budget. Even less expensive stopgaps, such as money for part-time respite care to give parents a break, are severely underfunded. About 11,000 families are on waiting lists for this service and others.

"It's bleak, in that society didn't plan and government didn't plan," said Nancy Meltzer, who helps aging families struggling with this issue at The Arc of King County.

"And for the most part, families didn't plan."

A looming choice

The flash of recognition came about two years ago. "We weren't getting any younger," Delores said.

Choosing a guardian to care for James after they were gone was the most straightforward part. They thought about James' sister, Linda, but quickly realized she wouldn't quite work. She lives in Arizona and has worries of her own. Mary was the logical choice. Mary and Bruce agreed, much to Delores and Allen's relief.

"As long as there's Mary, I'll never be worried about him," Delores said, her eyes tearing up.

Mary cares for James as if he were her own brother. They clearly enjoy each other's company.

On a recent visit, James was back to his old, buoyant self while he and Mary were out running errands.

"Ladies go first," he says with a sweep of the arm, as he held open the door to a party-supply store.

"My birthday is in March," he says again and again.

They stop at Starbucks, where he usually gets the same drink. But this time he can't remember what.

"Do you want something hot or something cold?" Mary prompts. "Vanilla or chocolate?"

She winds up ordering his vanilla Frappuccino for him.

She explained that the night before, James had stayed at their house and she reminded him to use the bathroom after dinner. He was in there so long Mary checked on him.

"I found he had taken his shirt off and was shaving," she said. Before bed, she reminded him once again and the same thing happened.

Every day, it gets harder for James to do the things he's done on his own for years.

Life is uncertain.

Initially, Mary considered having James live with her family when the time came. But now that he's showing signs of dementia, it doesn't seem possible.

"I can't do 24-hour care," Mary said apologetically. "I have three kids; I don't know if that's fair to them."

Mary has been planning. Maybe the Jensens could move into an assisted-living facility together. Maybe, in the meantime, Delores could sign up James for more state services, so the family could get help. Maybe, when Delores and Allen are gone, she could find a wonderful group home for James near her house.

When Mary brought all this up with Delores a few months ago, Delores began to cry.

"She doesn't want to talk about it," Mary says.

She sighs.

Delores' plan, she concludes, is to live forever.

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