

Uneven Care
**As Parents Age,
Agencies Struggle
To Help Disabled**

**Poor Ohio County Faces Strains,
As Funding Varies Sharply
From One State to Another
A Seven-Year Wait for 'Payday'**

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MCARTHUR, Ohio -- Bill Bare, a 41-year-old man with Down syndrome, lives with his mother. Now 74, she relies increasingly on a county agency, which has someone drive her son to doctor's appointments and provides him with a job, running a machine that glues bottoms on cardboard tubes. But it can't provide him with what she'd most like him to have: speech therapy.



Bill Bare

Mr. Bare's tongue is larger than normal, his rounded words often melting indistinguishably together. He routinely orders cheeseburgers at local restaurants, because the word is easy for him to say and for waitresses at Rita's and the Harvest House to understand. His mother can understand him, but says it would ease her mind if everyone else could, too.

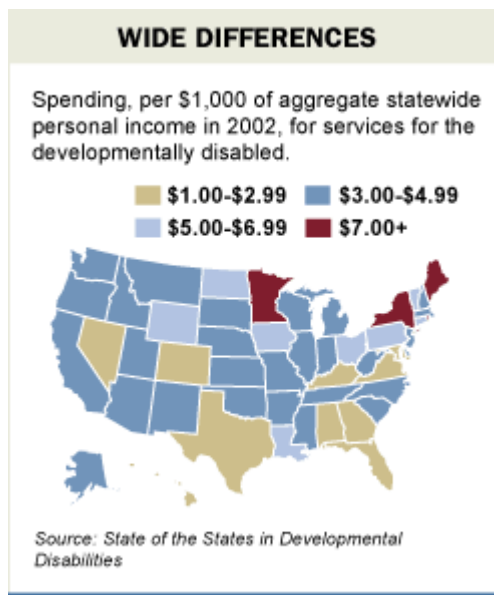
"What his mother wants is so simple: A speech therapist so people can understand her son when he talks. It's not going to happen," says Jackie Bowling, executive director of the Vinton County Board of Mental Retardation/Developmental

Disabilities, the agency that serves Mr. Bare and others like him. She worries about Mr. Bare getting lost and not being able to clearly say where he lives, or being unable to telephone for help.

If Mr. Bare lived across the county line in bigger and wealthier Athens County, he could have speech therapy. But Vinton County, where both poverty and unemployment hover between 15% and 20%, doesn't have a speech therapist, or physical or occupational therapists. Ms. Bowling can't afford to replace the nurse, who left two years ago. This spring, the state said it was cutting funding to county agencies 1% this year and 2% next. At the same time services are stretched, more people are coming to her for help.

"Once a month, I get a call from someone saying they never thought they would need our help, but they just can't do it anymore," says Ms. Bowling.

An aging population is straining agencies that help disabled people stay in their homes. Thirty years ago, most of the developmentally disabled lived in institutions. Today nine out of 10 live in private homes. That transformation



reflects efforts by parents who insisted their fragile child remain with them. Home care also turned out to be much less expensive than institutions.

Now many of these parents, growing frail themselves, can no longer do everything for their disabled adult children and are increasingly turning to government-funded agencies for help. Nationwide, more than 700,000 disabled people live with caregivers who are more than 60 years old, up from about 673,000 in 2000. For poorer counties, historically thinly staffed and lagging in services, the already large disparities threaten to grow even greater.

Here in Vinton County, the average spending for a developmentally disabled person was \$2,500 a year in 2003, compared with the statewide average of \$17,700. Other counties have swimming pools to help people with cerebral palsy move their muscles and special computer programs so people with autism can type their thoughts. Vinton doesn't. In this depressed county, voters rejected a levy to fund disabled services 18 times in a row.

Ohio reflects the national inequities in services for the developmentally disabled - in spite of more than a decade of legislation and litigation designed to eliminate it. The Americans with Disabilities Act, passed in 1990, was meant to assure equal opportunities for the 4.56 million Americans with developmental disabilities. Since that time, federal spending for community services has more than tripled to \$13.6 billion in 2002.

But federal money covers only a portion of what states need. And while there are some minimum federal standards for the disabled, such as hospital care, it's largely up to each state to determine what other services it will offer and how much it will spend.

"Give me your zip code and I can tell you the quality of care you will get," says Charlie Lakin, director of a University of Minnesota program which tracks services for the developmentally disabled. "I think it's terrible, frankly."

Nevada, for instance, spent \$1.26 for each \$1,000 of total state personal income for developmentally disabled services in 2002, the lowest in the nation. By contrast, Maine spent \$7.39, the highest level, according to a report compiled by the University of Colorado. The national average is \$3.94.

In Ohio, the disparities are even more pronounced, varying from one county to another. Unlike most states, each of Ohio's 88 counties has to pass its own special levy to fund most community services for the developmentally disabled.

Vinton County voters' repeated rejections of the levy, spanning more than a decade, forced drastic cutbacks. The agency eliminated a program for disabled preschoolers. Frances Malone, in her mid-70s and no longer able to drive long distances, asked if someone at the county could take her disabled son to dialysis three times a week to the closest clinic, about 50 miles away. She was told no. Denise Zimmerman wanted her mentally disabled son to join a county program that teaches job skills. She was told he'd have to wait until there was funding. Her son waited seven years.



Jackie Bowling

A year ago, the Vinton agency was about to close its workshop, which teaches job and independent-living skills to the developmentally disabled. Worried parents, some in their 70s, went door to door with their disabled children, asking voters to support the levy.

It passed -- by 18 votes -- giving the agency a tenuous, three-year reprieve. Ms. Bowling promised people she would use the levy money for services they never had before, such as speech therapy. Then she received word of the state funding cuts, putting a damper on some of those hopes. "I can't keep my promises," she says.

She came to Vinton County two years ago, after a 25-year career in Dayton. The agency she left behind had full-time nurses, therapists and staff devoted to finding jobs for the disabled at corporations such as Marriott Corp. Many experts say that's a better way to employ the disabled rather than segregating them in their own special workshop. "We don't have those options," says Ms. Bowling.

Most mornings, a county van picks up handicapped people at their homes, and brings them to the county's warehouse-like workshop, where they can earn a small paycheck. Some are taught to use vacuums, and sent to clean county offices. Others work at the agency's recycling center or assemble empty gun-powder canisters for Austin Powder Co., the area's biggest employer.

The agency is in McArthur, pop. 1,800, a town of neat houses, surrounded by forests, lumber yards and a few strip mines, mostly idle. Outside, bundles of cardboard and hundreds of aluminum cans, wait to be recycled. Mulch is piled out back, next to a greenhouse, donated by a local resident. The agency sells the mulch and, if they can get electricity and water to the greenhouse, Ms. Bowling plans on selling plants and vegetables, too. "We do anything to bring in money to keep the doors open."

Two years ago, a dozen people attended the county's workshop program. Now more than 40 do. Often, people don't come to Ms. Bowling's attention until a parent dies, and some other caretaker calls for help. Some parents are now going into the hospital themselves or can no longer drive their disabled child around. One mother called because her adult son fell, broke his eyeglasses and needed a new pair. Another older mother said she couldn't pay her utility bills last winter to heat the home she shared with her mentally disabled adult son.

This summer, Bill Bare's mother stopped into Ms. Bowling's office and told her the doctor had insisted she could no longer postpone having both knees replaced. She was reluctant to ask for help. "I was quite independent in the past," Ms. Bare says. The few days at the hospital stretched into weeks away from her son, with an unexpected stay at a nursing home for physical therapy. Ms. Bowling arranged for someone to stay with Mr. Bare while his mother was gone.

Such unexpected expenses can take a sizable portion out of the agency's resources. Tami Bay, who is in charge of the agency's budget, won't allow staffers to buy notebooks, telling them to use scrap paper. At a recent meeting in Columbus, a colleague from another part of the state handed Ms. Bowling a bag of pens, having heard her agency ran out.

It's only a matter of time until the Malones will need more help. Frances Malone, now 78, went to the hospital this summer to have a stent placed in her heart. She needed someone to watch over her two adult mentally disabled children, who live with her in a tidy trailer on a rural back road. While she was in the hospital, staff members worked with her 51-year-old daughter, Sandy, teaching her how to dial 911.

"I've explained to my children that one day when I'm not here, they will have to live somewhere else. ... They've accepted that," says Mrs. Malone. "They want to stay in their own home as long as possible."

It's not clear who will care for many developmentally disabled people after their parents are gone. Parents often hope their children will be able to live on their own, or in small group homes, with some outside help. But help isn't always available. An estimated 80,000 people nationwide are waiting to get services to help them stay in their communities.

"We're still playing catch-up after having ignored the problem for several generations," says David Braddock, professor of psychiatry at the University of Colorado, who has been compiling the "State of the States in Developmental Disabilities" report for 25 years.



Clare Ansberry

Sandy Malone (standing), 51, and her nephew, **Don Malone**, 38, sitting, both mentally impaired as a result of an inherited genetic disorder, at the workshop for the developmentally disabled in McArthur, Ohio

One problem is a big funding imbalance. Last year, 56% of Medicaid's long-term-care funds went for the developmentally disabled living at home or in small, community-based settings -- even though that's where 90% of them live. The rest of the money went to larger, full-time staffed homes or institutions, which house only about 10% of the developmentally disabled. Large institutions are usually considered less desirable because they segregate the disabled and are more expensive to run because of their size and staffing.

Still, some institutions are needed for the more-frail disabled population. A sudden switch of funding to private homes could cause the institutional network to collapse, Health and Human Services officials say, which could be devastating to those who

need such care. Congressional approval is needed to change any portion of Medicaid.

The critical component in community housing for the mentally disabled is a waiver program -- a program states aren't required to offer. The federal government reimburses states a certain percentage for home and community-based services for each person who gets a waiver. Reimbursement is based on average state income, with poorer states getting more. In Mississippi, for instance, the federal share is 77% and the state share is 23%.

In Ohio, the federal share is 59% -- and each county has to come with the bulk of the rest. In years past, Ms. Bowling's agency has had to pass up the federal waivers, because the county couldn't come up with the matching funds. This year, her agency was able to afford six waivers. Four went to disabled adults whose older parents could no longer care for them.

The agency also gets money from the state, including one fund, called Family Resources, which amounts to about \$500 for each disabled person's family. The money can be used as needed, to help people stay in their homes. One Vinton County woman, unsteady on her feet, couldn't safely negotiate the uneven clumps of dirt and patches of frozen mud outside her home. Her family used their allotment to pay for a load of gravel.

Tami Wiseman used hers to build a wheelchair ramp for her 6-year-old granddaughter, Abby, who lives with her and her husband.

Abby was born with cerebral palsy and a neurological disorder. She can't walk, sit up or swallow properly. She can say about 10 words, including Ma and Up. Ms. Wiseman, who says Abby's parents haven't been involved in her care, has permanent custody of the child.

Abby's bedroom sits at one end of a trailer, crowded with a hospital bed and a half-dozen machines to monitor her heart rate and breathing. Pink and purple outfits are stacked on top of the dresser, unable to fit in the already full drawers and closets. "I don't know what else to get her. She can't ride a bike," says Ms. Wiseman. Abby, bright-eyed, lays in her bed watching Bert and Ernie on the television in her room. Oxygen tanks stand on the front porch.

Abby was admitted 21 times to the hospital in the last year. At night, when her heart rate drops or her breathing tubes get clogged, a monitor goes off. Ms. Wiseman, a registered nurse, rushes to suction her lungs. A combination of federal and local funds pays for someone to come stay with Abby five days a week. Because Abby needs 24-hour care, the county also pays Ms. Wiseman for her nursing services, since the agency doesn't have a nurse of its own.

Ms. Wiseman raises rabbits in her yard. The wheelchair ramp made it easier to get Abby outside to see the rabbits.

In other counties, with full-time nursing staff, severely disabled children can go to day programs and be with other children. Physical therapists can work with their muscles. Those options don't exist for Abby. "There's a whole group of people that we're not serving," says Ms. Bowling.

A handful of mentally and physically disabled people, some in their 30s, live in the local nursing home because their family can't care for them any longer and there are few housing alternatives available. Ms. Bowling says those people would benefit from coming to the agency's workshop, "if for no other reason than to get in a van and take a ride and see some other folks. Just from that perspective, people could gain so much." But most of these people have catheters that must be changed regularly. Without a nurse on staff, the agency hasn't been able to bring them in.

Several weeks ago, the Elks Club in neighboring Jackson County gave Ms. Bowling a \$2,500 check. She's going to use it to buy a special board so her staff can safely transfer people out of wheelchairs. If there's enough left, she wants to buy a recliner that vibrates to stimulate the muscles of those who can't move them on their own. It would go in the small, windowless room off the workshop floor, officially designated as a tornado shelter, but which she wants to dedicate to the more severely disabled.

Many county agencies have rooms especially for the severely disabled. These rooms, some the size of a gymnasium, can be filled with massage tables, colored lights, soft music and interactive toys to provide stimulation for those who can't

talk or walk. Special chairs dangle from the ceiling to give the wheelchair-bound a place to be besides their wheelchair.

Without the money to buy such things, Ms. Bowling and staff member Diane Arthur foraged through a storage trailer out back, filled with donated or discarded items. They pulled out a green gym mat, a few big wedge-shaped pillows, balls and Mickey Mouse "See 'N Say" toys. "We're trying to make do with what we have so we don't have to buy anything," says Ms. Arthur.

Inside the room, Ms. Arthur sat on the floor and clapped her hands to get the attention of a 19-year-old with cerebral palsy and autism. The young woman rolled off the gym mat where she had been laying, and onto the linoleum floor. "That's why we would like to get some carpet in here," says Ms. Arthur. A staff member brought in a stuffed monkey that sings "Pop Goes the Weasel" when moved up and down. The 19-year-old shook the monkey into song.

Ms. Arthur doesn't have any special training in physical or occupational therapy. "We're not able to pay for a degreed staff," she says. "When you don't, folks get a different level of services." After the levy passed, Ms. Bowling was able to hire a specialist to work with the families of disabled preschoolers.

Outside Ms. Bowling's office is a framed copy of a front-page article that ran in the Vinton County Courier under the headline, "After 18 tries, MR/DD finally passes levy." Twenty-seven-year-old Brian Zimmerman, who suffered brain damage from a virus his mother had when she was pregnant, is quoted as saying, "I'm happy. Are you happy? I'm really happy."

Mr. Zimmerman's mother tried in 1995 to get him into the adult workshop so he could meet people and have a job. With his mother working as a cashier at Supervalu and his father driving a forklift for a cereal company, he had little company and little to do. Kids his age were uncomfortable around him.

"Nobody comes for Brian, and says 'C'mon, let's go to a movie or down by the river,' " says Ms. Zimmerman.

Instead, her son would wake up, shower, eat breakfast, go out on the front porch and wait for the mailman. In the winter, he waited inside, looking out the window in anticipation of the afternoon delivery. He did that for seven years until there was an opening for him at the county agency.

Now Mr. Zimmerman has a job gathering and bundling cardboard, as part of the agency's recycling program. The agency uses the money it makes from recycling to pay its workers. Every other Friday, "payday Friday" as he calls it, he wears a red Wal-Mart hat, to celebrate his \$75 to \$150 pay and pending shopping trip.

Ms. Bowling thinks some of the agency's clients could do well working in the community. But Vinton County doesn't have enough resources to train people to scout for jobs and coach disabled people in the workplace. And in a place where unemployment is persistently high, there aren't many opportunities in the private

sector. Instead, the agency creates jobs that its adult clients can do, often for other county agencies.

At the workshop, Don Malone has sanded long strips of wood that will become devices to pull racks out of an oven without getting burned. The local fair-housing office has ordered 700 of them. "I'm really proud of myself after I accomplish something," says the 38-year-old, as he held one up for inspection.

Mr. Malone, who is mentally disabled due to the same genetic disorder that affects his aunt and uncle, looks forward to the county van that picks them up most days and takes them to the workshop. "He has the skills to do more," says Ms. Bowling, "but that's all we have to offer him."

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