

Advocate defies doctors, fights to help disabled

BY BETH MILLER
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From the day she was born -- May 24, 1966 -- plenty of people knew where Jamie Wolfe belonged.

In an institution.

That's what doctors told Sheila and Martin Wolfe when their second daughter was born.

That's what doctors said again when Jamie Wolfe was about 9 years old and struggling emotionally with her life.

That's what some advisers said three years ago when she got pneumonia, slipped into respiratory failure and almost died.

In an institution.

Each time the answer was the same.

"No," said her family.

"No," said her friends.

"No! No! No!" said Wolfe.

Jamie Wolfe was born "like a pretzel," Sheila Wolfe said -- her limbs and torso twisted by arthrogryposis, a condition that left her with no muscular development in her arms and legs.

When a doctor saw her as an infant and made the first "institution" suggestion, "my husband almost beat him up," Sheila said. "As long as she was able to function in the world, there was no chance that was going to happen. We weren't ashamed of her."

Jamie Wolfe is now 39 and living in her own apartment in Dover.

But it's not easy.

She needs help from attendants to do the most ordinary things -- like get out of bed -- and she has never been able to walk.



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Using the table to help support her cell phone, Wolfe speaks to her mom after teaching a class.



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Jamie Wolfe buys a snack at the Trabant Center at the University of Delaware.



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University of Delaware worker Nacole Gardner helps Jamie Wolfe by putting a straw in her drink at the Trabant Center. Wolfe drinks everything through a straw because she can't lift a cup or glass to her mouth.



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Wolfe teaches a seminar on disabilities at the University of Delaware as a member of UD's adjunct faculty.

Things people say that makes her eyes roll

- Do you have a license?
- Do you have a horn?
- Do you go through the car wash in that?
- You look so cute in that thing.
- Do you want to drag race?
- Let me put my hands on you so I can heal you.
- You're speeding!
- Can you have sex?

JAMIE WOLFE

Age: 39

Residence: Dover

Occupation: Disabilities specialist for the Center for Disabilities Studies at the University of Delaware

Education: Master's degree, Delaware State University; bachelor's degree, University of Delaware

Family: Single

Two things she wishes legislators would endorse for those with disabilities:

Money follows the person. Following an assessment of needs, this shift would direct resources toward the person who needs the services instead of toward the programs that deliver the services. This would give consumers greater choice in who provides the services and how they are provided.

Medicaid Buy-In. This program would cost the state about \$2 million and would allow those now eligible for Medicaid to work full-time jobs without losing Medicaid eligibility. They would accept health benefits offered to other full-time employees and rely on Medicaid to cover services the health package doesn't cover. Each person would buy Medicaid services (on a sliding scale) and have greater choice on providers.

Places she'd go, if she could get there:

She can't hold a phone up to her ear or use a fork to lift food to her mouth.

She drinks everything -- including coffee -- through a straw, because she can't lift cups or glasses.

Lots of stuff gets in her way, stuff most people would never notice unless they found themselves in a wheelchair, shut out of their favorite restaurant, without a ride on Sunday when public transit doesn't operate, or packing up a few things to move to a nursing home because the struggle seems too great.

But those things have met their match in Jamie Wolfe. She may not have much muscle, but she has lots of fight.

"And I'm glad she does," her mother said. "Otherwise, she'd end up in a corner somewhere, drooling."

'A perfect guinea pig'

From her childhood, Jamie Wolfe has been on the front lines of this struggle for independence.

After the "Education for All Handicapped Children Act" was passed in 1972, requiring that children be taught in the least-restrictive environment, she was the first to leave the segregated "special school" -- known then as Kent County Orthopedic School -- to take classes in William Henry School, where all the other kids went.

She started with one mainstream class in fifth grade and by eighth grade was in that school full time.

"I was a perfect guinea pig," she said. "The teachers couldn't keep up with me. I was in above-average or honors classes."

What she wanted then as a kid is the same thing she wants now as an adult -- to be acknowledged as a human being, with the same feelings and challenges.

"I don't want people to see me as a courageous little gimp," she said. "It's not about that. It's about getting things done."

She often testifies at Legislative Hall -- where she challenges lawmakers to make life better for those with disabilities -- and trains others to deliver effective testimony. She does her homework, asks good questions.

She has a master's degree in social work, works as a policy analyst at the University of Delaware's Center for Disabilities Studies, and teaches a seminar on disabilities as a member of UD's adjunct faculty.

She chairs the Delaware Developmental Disabilities Council and fights for the rights of anyone with a disability to live their lives freely and fully.

"I think she was born that way to do what she's doing,"

The Lobby House, a popular Dover tavern near Legislative Hall. She doesn't go there because the restrooms are not accessible to those who use wheelchairs.

Sambo's, Leipsic. Three or four steps come between her and the seafood she craves.

Swimming. Because of her catheter, she can't swim in public pools, she said.

her mother said. "Everything has a purpose in life, and that's what I think she's here for."

Dealing with the situation

Those who assume Wolfe wants help with everything will learn quickly that she wants to do as much as possible for herself.

She has come to terms with her condition and needs others to do likewise.

"When I was younger I thought it was unfair," she said. "I would hear people talk about college and going out on dates. I don't have any of that, I thought. Will I live with my mother my whole life?"

One vocational rehabilitation evaluator told Wolfe she would never be able to handle college. She should be a receptionist.

Since then, Wolfe has graduated from Delaware Technical & Community College, then the University of Delaware, and then Delaware State University, where she earned a master's degree in social work.

She learned quickly, though, that social work was not for her.

"I hate social work," she said. "I'm not patient enough. I get frustrated. You have two kinds of people -- people who couldn't get the services they needed or people who get a lot of services and won't take responsibility for themselves."

She doesn't want to be in either of those categories herself, so she works for legislation that will protect the rights of those with disabilities, provide the services they need and fix problems they face.

"I'm living what I'm trying to do," she said.

When she recovered from the near-fatal respiratory illness in 2002, she returned to her mission with extra passion.

"I almost lost everything," she said, referring to her liberty, not her life. "Part of it is the way the system is set up, part of it was because I was afraid to ask for more services. I was afraid they'd put me in an institution."

Adjustments made

Freedom comes with a price, Wolfe knows, but the price of living free is nothing like the price of life in an institution. That life takes a high toll on human dignity, she believes.

"Nobody needs to be in a nursing home," she says.

To live in her own apartment, some renovations have been made. The tub was removed from the bathroom to allow her to shower in a chair. Items are placed so she can reach them from her chair. And all the furniture is placed

to accommodate her chair's 25 1/4-inch width.

Many details of daily life -- bathing, dressing, cooking, cleaning -- Wolfe leaves to the attendants who visit for 12-hour shifts. She gets help from Medicaid and other sources to pay for them. Because she has sleep apnea, Wolfe needs an attendant overnight to monitor the machine that keeps air pressure consistent so she doesn't stop breathing.

Medicaid pays for her chair, her four medications and other necessities.

She would help with more of the cost if she could, she said. Passage of the "Medicaid Buy-In" plan would allow her to work full time without losing her Medicaid eligibility.

Medicaid would cover whatever her employee benefits did not cover, and the plan would also allow her to pay for some of her Medicaid coverage. It would give people with disabilities many more options on how and where to invest their time and talents.

She would love to work full time at UD, but she would make too much to qualify for Medicaid and not enough to cover her needs.

"She's a valued employee ... and it would be much easier to consider her for a full-time position if she didn't have that [Medicaid eligibility] constraint," said her boss, Michael Gamel-McCormick, director of the Center for Disabilities Studies. "She's a master's level person and should be making a certain level of money."

Instead, she works part time for low pay to stay eligible for the assistance she needs to stay independent.

Wolfe sees this fight as a continuing struggle for civil rights.

"In the 1960s, when African-Americans wanted to ride the bus or eat in a restaurant, they weren't institutionalized when they couldn't," she said. "That's what it comes down to."

Battling prejudice

Continuing prejudice leads to laws that reduce the value of a person to their apparent usefulness, how much of a burden they seem to be, whether others consider their lives to have quality or not. It is shallow, skin-deep thinking about human beings, and Wolfe despises it.

"It comes back to people seeing disability as a death sentence," Wolfe said. "They say, 'I can't live in a wheelchair.' "

Many people will, though -- and not by choice.

"A parent has never dropped to his knees in church and prayed, 'Please let me have a child with disabilities.' No one says please let me have it, it's my lifelong goal," Wolfe

said. "But we need to get past the point that disability is bad."

Breaking free is tough for many, Wolfe said, because life in institutions can produce a prisoner-like mentality. In a prison, there is structure. In life outside, there are challenges. Some fear they will fail when faced with those challenges.

That's why Wolfe's favorite movie is "The Shawshank Redemption." It addresses the prisoner mentality and carries the tag line: "Fear can hold you prisoner. Hope can set you free."

Whatever else other people may think, Wolfe knows which side of that equation she belongs on.

She lives in the land of the free. And she aims to stay there.

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