

# Amanda O’Keefe: Law Student Untangles Web of Services for the Developmentally Disabled

Amanda O’Keefe launched LEAD to improve her sister’s quality of life and ease the plight of caregivers in her community.

BY LISA INTRABARTOLA



**Amanda O’Keefe’s only sibling, Paige, has Turner syndrome and experiences severe developmental delays and lack of motor coordination. Paige requires care around the clock.**

Amanda O’Keefe watched her mother devote hours a day hunting unsuccessfully for programs that could help Amanda’s developmentally disabled sister, Paige.

She thought: You need a lawyer to navigate the state’s human services labyrinth.

Or a law student.

Inspired by her family’s struggle, O’Keefe launched Learn Empower and Advocate for the

Developmentally Disabled (LEAD) during her first year at Rutgers Law School in Camden. The pro bono project tracks down and shares information about services available for families like hers in the Camden area.

“You really shouldn’t need a law degree to access these services. It’s just that the systems are so broken,” says O’Keefe, who graduated with her J.D. in 2016. “The people on the front lines don’t know the system themselves. Higher up, I don’t think the right hand talks to the left.”

O’Keefe’s only sibling has Turner syndrome, a chromosomal disorder in which a female child is born with a missing or partially missing X chromosome, causing stunted growth and infertility. Symptoms vary greatly, with some women going undiagnosed until their childbearing years. Others, including Paige, experience severe developmental delays and lack of motor coordination, and require around-the-clock care.

“For many years I had a hard time accepting she was not going to grow up ‘normal,’” says O’Keefe, a Berlin, New Jersey, resident who earned a bachelor’s degree in criminal justice from Rutgers University–Camden in 2013. “It was always, ‘next year.’ Next year, they are going



**O'Keefe and her sister, Paige, at home.**

to get her medication right and she's going to be able to do everything she couldn't do this year.

"Next year never happened."

O'Keefe learned to accept Paige's reality but vowed to never accept "no" for an answer when it comes to improving her sister's quality of life.

"I really hate the word no," she says. "Once I get my mind set on something, I spend as much time as it takes to get it done."

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LEAD was born out of that tenacity and fierce protectiveness. The idea came to O'Keefe after her family stumbled upon a life-changing respite service for Paige—a family support program through the state Department of Children and Families that provides free supervised weekend outings for individuals with special needs.

"My family is continuously busy with doctor appointments, talking with insurance companies, and taking Paige to therapy, and respite is a huge help. It gives us a little break and allows Paige to experience new things," she says. "But we would have never known about respite if we did not happen to talk with the right person."

If her family was unaware of respite's existence, O'Keefe wondered, how many other opportunities was Paige missing out on? And do families like hers experience this much frustration securing services they are legally entitled to?

A summer spent interviewing Camden-area families with special-needs members and tracking services, eligibility requirements, and application processes confirmed what she'd suspected was true.

During this research—funded by a Horace and Kate King Wu fellowship—O'Keefe learned which buzzwords to use, questions to ask, and automated prompts to follow to get results for Paige and her peers. For example, she found the ability to secure valuable services for a loved one hinges on whether a caregiver understands the importance of the phrase "substantial functional limitations."

"Families are so used to looking at everything their son or daughter can do. They don't want to think about what they can't do," she says. "But when you are trying to find these services, you have to highlight what they can't do."

O'Keefe, empowered by her newfound knowledge, was eager to help others unravel the tangled web of resources. Originally, she intended to offer families pro bono representation through LEAD. But Jill Friedman, an adjunct professor and acting assistant dean of the pro bono and public interest program at Rutgers Law School in Camden, persuaded her to focus on sharing information and advice through public support sessions. Friedman also connected O'Keefe with the person who would become her mentor, professor, and employer, Herb Hinkle, a 1974 Rutgers Law School

alumnus and celebrated adjunct professor who has dedicated more than 40 years to championing special-needs clients.

“With Amanda it has just been one extraordinary episode after another,” says Hinkle, founding partner of Hinkle, Fingles, Prior & Fischer. “I was her adviser on LEAD, but she really didn’t need much in the way of advice. She went out and interviewed just about every player in the disability field that had something to contribute toward her gaining an understanding of the services and how they are implemented.”

Ultimately LEAD became a platform for O’Keefe to promote the plight of the develop-

the youngest member of the New Jersey State Bar Association’s Blue Ribbon Commission on Unmet Legal Needs, co-chaired by former New Jersey Supreme Court Justices Virginia A. Long, a Rutgers Law School alumna, and Helen E. Hoens.

Hinkle marvels at his mentee’s ability to invest close to 300 pro bono hours running LEAD while juggling her studies, community outreach, internships, and relationships with friends, family, and fiancé, James Paoletti.

“It’s almost spooky, isn’t it?” Hinkle says when asked about O’Keefe’s work ethic. “Let’s just say when I was graduating from law school I had some involvement with this stuff. Where she is now is head and shoulders above where I was.”

That’s why the now-retired Hinkle helped O’Keefe secure an internship with his former firm, where after graduating she planned to work as an associate concentrating in adult services, estate planning, elder law, and education law—all tailored to clients with disabilities.

“All the attributes you expect a lawyer would someday possess, she possesses now,” he says. “She’s way off the charts. She’s very special.”

But O’Keefe is quick to downplay her laundry list of extracurriculars and achievements. “It always feels like I should be doing more,” she says.

Whether that’s putting in a few more hours trying to teach Paige how to ride a bike or tracking down another elusive service for her, taking care of her sister is something that comes naturally to O’Keefe.

“All my career goals have centered around my sister,” she says. “I just want her to be happy.”



**O’Keefe helps Paige with a writing lesson.**

mentally disabled and better their situations. LEAD research, compiled with the help of three law students, is now stored in a database—its information publicized and disseminated through public presentations for caregivers, doctors, social workers, and educators. Since founding LEAD, O’Keefe was appointed to the board of directors for the Arc of Camden County, served as a student representative to the Rutgers University–Camden Chancellor’s Disability Advisory Council, and was made