

Disability advocates learn to speak out

LAUREN KENT | PUBLISHED 10 HOURS AGO



8-year-old Nickolas Vlasaty poses on the staircase in his home. Jennine Vlasaty witnessed her son falling behind in school and enrolled in Partners and Policymaking.

Photo by Beren South / The Daily Tar Heel

Jennine Vlasaty's 8-year-old son Nickolas was born with Down syndrome. For most of his schooling, he was able to attend typical elementary classes and interact with his peers. But in the last two years, Nickolas has been pulled out increasingly for special education classes.

His mom witnessed him falling further behind in the curriculum and decided to do something — not just to advocate for her son, but for all children with disabilities.

Vlasaty enrolled in Partners in Policymaking, a program through the N.C. Council on Developmental Disabilities that teaches people with disabilities and their parents how to take part in policy

workshops. After eight workshops on topics such as membership and government, the program culminates each year with a presentation to a panel of N.C. General Assembly members.



"It just opened my eyes on how to get more involved so I'm at the table," she said.

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As a result of the eight-month program, Vlasaty has joined several committees and is applying for a spot on the state advisory council on education for kids with disabilities.

Program participants brought a wide-range of issues to the General Assembly, such as low participation in disability awareness month, the lack of specialized disability training among in-home care providers and unreliable transportation.

But they also tackled more complex issues, such as Managed Care Organizations, which offer support services to people with disabilities through Medicaid coverage. Disability advocates question laws that allow these organizations to keep

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excess money not spent on patient care. Meanwhile, the waitlist to receive these services can be 10 years long.

Deborah Whitfield, project director for Partners in Policymaking in North Carolina, said the legislators were moved by the presentations.

"(Participants) used their personal life stories — and the pain of the stories," she said.

Partners in Policymaking is part of a larger self-advocacy movement in the disabled community.

The program began in Minnesota in 1987 and has expanded internationally. More than 27,000 self-advocates and parents have graduated.

Colleen Wieck, co-founder of the program and executive director of the Minnesota Governor's Council on Developmental Disabilities, said she got the idea while listening to a mother speak at a congressional hearing on Medicaid.

"She was given lots of stage direction. Somebody would say 'Whatever you do, don't read the script,' and somebody else would say 'Stick to the script,'" she said. "We came back to Minnesota and thought, 'why don't we actually teach people how to communicate with local officials, state officials and federal officials?'"

She said the program was also designed to put self-advocates and parents in the same room.

"The whole world changes because you see a bigger picture," she said. "You realize, what will my child do in 10 years?"

Partners in Policymaking graduate Kristian Champion, who uses a wheelchair, was encouraged to advocate for herself at a young age.

"We don't want to be stuck under the bubble of mom and dad," she said.

Vlasaty said she hopes her son takes part in the program when he is old enough.

As an adult on the autism spectrum, Raleigh resident Christopher Smith said he enrolled in the program to become a self-advocate.

He said self-advocacy is important because those with disabilities should not always have to rely on others.

need) unless you tell them. I'm going to try to be that face out there for my people."

Wieck said Partners in Policymaking is constantly updating and supporting more advocates to pursue reform.

"Instead of accepting things the way they are, we should keep challenging the system."

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