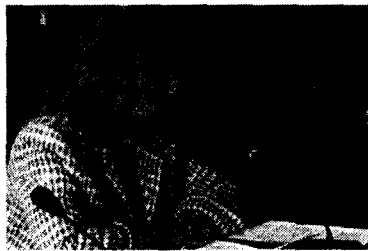




## DO DISABLED, THEIR FAMILIES NEED OMBUDSMAN TO DEAL WITH MAZE OF SERVICES?

COLLEEN O'DEA | JUNE 23, 2016

Cautious welcome for effort to help people 'navigate the bureaucracy,' but concerns raised about adding another layer of complexity



Assemblywoman Valerie Vainieri Huttle (D-Bergen).

New Jersey offers a host of services for those with intellectual and developmental disabilities, but they are located in several different state offices and it can be difficult for the disabled and their family members to get — or even know about — what's available, advocates say.

Legislation scheduled for a vote Monday in the Assembly aims to make navigating the maze of services easier by creating the position of ombudsman to provide information about services available, assist those involved in disputes with state agencies,

keep track of common complaints, and suggest improvements. If approved, the ombudsman would have duties similar to those of the Special Education Ombudsman created earlier this year.

Assemblywoman Valerie Vainieri Huttle, D-Bergen, sponsored the legislation (A-3824) because, she said, she regularly hears from people having trouble getting services and she thinks an ombudsman's office would be the best way to help. (The bill would have the governor appoint the ombudsman.)

"I get numerous phone calls to the office from people trying to navigate the system, not only trying to navigate it, but telling me their services were terminated. They don't know where else to go," she said. "The ombudsman would serve as a GPS to help people navigate the bureaucracy. It would be like a one-stop shopping place with a wealth of information."

About 25,000 adults and almost 15,000 children receive support from the two major state agencies charged with providing services: the Division of Developmental Disabilities (DDD) in the Department of Human Services and the Children's System of Care (CSOC) in the Department of Children and Families. Services include early intervention, community-based day programs, group home or other residential services, in-home supports, summer camps, respite care, home and vehicle modifications, and assistive technology, among others.

The ombudsman's office would not be located in either DHS or DCF, but instead, would be in, but not of, the Department of Treasury and would provide information and communication to help resolve disagreements among those with disabilities and the departments providing services.

Frank X. Caragher, executive director of the Arc of Union County, said it is unfortunate, but people do need someone such as an ombudsman to help them get the help they need.

"It is a sad situation when parents and families require an outside representative, the ombudsman position, to oversee how the Department of Human Services and the Department of Children and Families impact their lives," he said. "What occurs in the lives of people with intellectual disabilities these days is governed so much by the state budget. The effort to access services is exhausting. The information provided is not easy to digest by someone not in the field every day. Though families are promised choice and a service designed to meet their child's needs, our

experience has been that these are promises made by people without direct knowledge of what is actually happening in our communities."

While agreeing that it would be useful to give the disabled and their families another avenue for getting help, advocates are split over whether this is the best way to provide that assistance. Although a number of nonprofits and other organizations provide a certain amount of information and advocacy today, some working in the disabilities community say no one office currently performs the duties envisioned for the new ombudsman. Others do not want to see the office duplicate work already being done by other agencies.

The New Jersey Council on Developmental Disabilities is reserving judgment until it can get answers to the vagaries of the legislation, said Stephanie Pratico, its chair. "We really need to understand better what its role would be, what authority it would have," she said. "I think really what our community needs is some oversight and authority. If the ombudsman would be able to hold people accountable, then yes, that would be something useful ... The last thing we need to do is create another layer in there. The systems are complex enough to try to navigate."

Pratico said she was surprised to see that the ombudsman would be charged with working with the Developmental Disabilities Council, because she said the idea had not yet been discussed with the council.

Both Pratico and William Testa, executive director of the Arc of Morris County, a disabilities services organization, said they would not want the ombudsman to duplicate work already being done by others. But Testa did say, "given the complexity of the system, I can see having one office parents can go to for information; I can see having an entity outside the official government bureaucracies."

In 2013 the state split responsibility for disabled issues among the two departments. DDD now assists only adults, while responsibility for children with disabilities was moved to DCF's CSOC.

New Jersey designated Disability Rights New Jersey as the organization to protect and advocate for the rights of people with developmental disabilities. "It has gotten very complicated and I know a lot of people have gotten very frustrated," said Joseph Young, executive director. "I don't think it hurts to have someone out there trying to portray neutral information. We are there when the system breaks down."

Like Caragher, Young said it is "unfortunate there have to be all these specialty ombudsmen." In the past, people could get help by visiting an office on disabilities in each county, but these have been merged with the offices on aging and the system has become more specialized, making it harder for someone who does not work on disabilities issues every day to know what to do.

Young is concerned, though, where the state would find the money to fund the office. The fiscal note attached to the statement the Assembly Appropriations Committee issued on approving the bill on Monday estimates it could cost anywhere from \$150,000 to \$1.9 million a year, depending on "the design, operation and implementation of the office," with costs for staff and an annual report, among other items.

"The bill would establish an office, but doesn't give it any money to pay for it," Young said. "If the money has to come out of services, that would be a problem."

"I don't think we are talking about a lot of money," Assemblywoman Vainieri Huttie said. "I think it would be worth every penny of what it costs. It would not take away from services; it would be adding and making services available." Disabilities do not distinguish by party, she said. The assemblywoman hopes the measure will pass and not become embroiled in a political argument. It does have bipartisan support -- Sen. Minority Leader Tom Kean, R-Union, is sponsoring it in the upper house.

For Caragher, an ombudsman is just a first step. "Unfortunately, one person, independent, informed and credentialed, is not going to change or redirect the actions of the Department of Human Services or the Department of Children and Families," he said. "The difficulties that individuals and families must overcome to access the supports they seek and need is entrenched

in the present system. The required change must occur internally to both those departments if a lasting, positive outcome is to be achieved. These departments must realize again that they exist only to support and serve children, families and individuals."

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