Backers seek more funds for disabled

By Elise Takahama

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BOSTON -- Local disability advocates are expressing a mix of surprise -- and caution -- over Gov. Charlie Baker's proposal to significantly increase funding for the state's most vulnerable populations in his fiscal 2020 budget proposal.

Among several additions, Baker proposed $4 million more for the Department of Developmental Services budget, which provides funding to The Arc of Massachusetts, an organization that supports people with developmental and intellectual disabilities -- including autism, down syndrome, cerebral palsy and behavioral problems.

Baker's 2020 budget proposed sending $66.5 million to family support services -- $1.5 million more than the 2019 budget -- in addition to $10.5 million for at-home care and $25 million for programs for 21-year-old adults about to enter the workforce.

Professional caretakers ensure all these programs move smoothly. They generally help those with disabilities get dressed, use the bathroom, shop, take medication and sometimes even find a job, executive director Leo Sarkissian said during a recent webinar reviewing the current state of the workforce and budget proposals. They work long hours. They do their best to ensure those they work with are fully integrated into their communities.

"Each year the challenge is to serve new people while addressing evolving needs as adults age or have new medical conditions and/or other increased costs," he said.

But many caretakers are severely underpaid, said Mary Heafy, president of the Fitchburg chapter of The Arc, which serves about 350 people with intellectual and developmental disabilities.

This results in a high employee turnover rate and low morale for those who need services, Heafy said.

"When we're paying people $13.87, it's a struggle to be able to survive with one job," Heafy said in a phone interview Monday. "It's a struggle for employees to meet their own basic needs. So we see more turnover than we'd like to see. And that has a direct impact on the individuals we support."

This year, one of the big goals is to commit to paying entry-level workers a $17 per hour salary, she said.

"It's not going to be a small price tag, but we are going to be in a far greater crisis if we can't provide a workforce for our most vulnerable population," Heafy said. "And that could be on the horizon."

Jean Phelps, CEO of The Arc's Lowell chapter, said that while the new budget proposal gives her hope, she's concerned there's more focus on new people coming into the system and not enough on those who are already benefiting from The Arc's services.
"We've gotten really good at supporting people, and our folks are living longer and dealing with new health concerns," Phelps said. "And there's not a lot of money in the system to help accommodate the needs of the population as they age."

Some older people, for example, might need various health-related resources, clinical support or even a home modification -- for those who can no longer climb stairs to a second-floor bedroom, she said.

Instead, the Baker administration has proposed raising funds for the younger "Turning 22" class, which is made up of 21-year-olds who are aging out of special education but still need support. In 2019, Sarkissian said, 1,073 students will graduate from school needing adult residential or employment services.

As a result, Phelps said, the organization must "get creative" in managing the current system, while also figuring out how to expand and provide opportunities for younger people entering the program for the first time.

But the initial budget is an extremely gratifying testament to all the work they've done with their legislators, Phelps said.

"People want to have a life in the community that looks like everyone else's life," Phelps said. "That's our standard. That's the thing that keeps us moving forward ... And no matter what happens, we're going to see it through."