



NEW YORK STATE SENATOR

John W. Mannion

Central N.Y. organization addresses challenges faced by those living with autism

SENATOR JOHN W. MANNION April 8, 2024

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On their website, the CDC's Autism and Developmental Disabilities Monitoring Network says about one in 36 children have been identified with autism spectrum disorder.

Families of loved ones with autism face many challenges, and education, they say, is key. The Kelberman Center is an organization specializing in autism support and services throughout all stages of life.

They teamed up with Better Together at Redeemer, the Oneida County Sheriff's Office, and Learning the Language of Our Biggest Fans to hold an autism awareness listening/learning event and training in Utica on Saturday.

Increasing awareness, education, and training among law enforcement and first responders was discussed, and a specialized training took place.

But discussions also centered on other topics.

"Today, we are taking on, really, the complex nature of people with autism, their children, adults in their families face in terms of their care throughout their lifespan. And that includes medical, dental needs and includes access to services and provider agencies to

provide the supports that they need," said Maria Cappoletti, CEO of The Kelberman Center.

Advocates said going to the dentist, for example, can be challenging for some people who have autism.

"When you have sensory disorders and you're not communicative and you don't know what's next, the sights, the sounds in a dentist chair, the smells, all of those things can be very overwhelming. And it's hard for a person on the spectrum to sit still. So they do require general anesthesia for dental work," said Better Together at Redeemer Lead Faciliator Kathy Caruso.

"What we're finding is our individuals are on a long waiting list to get dental and long waiting list to get medical care providers. Just aren't there. And it's causing issues because the few that do it in the area just aren't experienced enough with autism population to handle their needs," said Steve Gonyea, a parent advocate.

Several lawmakers were also in the audience, including Sen. John Mannion, who has a son with autism.

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"With the disabilities community, what we've seen is really an underfunding of the system for almost a decade. So we need really not only robust support, but we need to be open minded in making sure that individuals have access to medical care, dental care and mental health beyond the services they might receive and the supports they receive related to their disability," Mannion said.

Other issues include dwindling numbers in the direct support care workforce, the hope for parents to be paid caregivers, and housing options as people with autism age, and of course, increasing awareness of these challenges.

"Certainly this month being April - Autism Awareness Month, we're always advocating and creating awareness all year long, but April certainly is an opportunity for us to share that information even more to people that may not have heard it yet," Cappoletti said.

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