

Families pick Rochester for its autism resources

Autism

But even integrated network still leaves some kids in need

Lauren Peace and Justin Murphy Rochester Democrat and Chronicle | USA TODAY NETWORK

Quinn Brady relocated to the Rochester area just less than a year ago, but living in New York was never a part of her original plan. ■ When Brady's son Robert was diagnosed with autism in August 2017, she and her family were living in Pinellas County, Florida, near St. Petersburg. ■ "Being a first-time mom, you don't always recognize problems, right? But I went to brunch with mothers at his day care and all these kids at my son's age are having full conversations," said Brady. "Robert wouldn't look at me. He wouldn't sit with me. He definitely wasn't talking to me about the food we were eating. That's when it really hit me. He's delayed."

Robert's diagnosis came on his third birthday during a visit to All Children's Hospital, a Johns Hopkins pediatrics hospital in St. Petersburg. During the visit, their pediatrician advised Brady to leave the state and go somewhere with better services for her son.

As a tech executive for a company with offices around the country, Brady had the professional flexibility to do so.

"He said New York is a fantastic place to be, especially the Rochester area because Rochester is part of the Autism Treatment Network and the state, county and school services are phenomenal," said Brady.

Three months later the Brady family moved to Pittsford.

The Bradys are not alone in relocating to Monroe County. The Rochester area has become a destination for out

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Vivian Sievers plays with stickers with her mother, Melissa. Melissa and Chris Sievers moved from Maryland, in part, to access more early childhood services for Vivian, who is autistic. MAX SCHULTE/ @MAXROCPHOTO/STAFF PHOTOGRAPHER



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of-state-families who have children with autism, drawn by New York state's early intervention therapies for infants showing signs of need. The services are free, but getting them demands time and self-advocacy.

Like Brady, Chris Sievers and his wife, Melissa, moved their family to greater Rochester from the Baltimore area after their youngest daughter, Vivian, was diagnosed with autism.

"Maryland had a lot of amazing clinical supports for autism but really didn't have the services available that we were looking for," said Sievers. "We weren't as happy with early intervention in Maryland, they didn't give us

very many hours, and they had one person trying to do everything. Monroe County had everything that we were looking for.”

Vivian’s therapy services jumped from one hour a week in Maryland to 20 in New York.

Sievers said additional community supports have made all the difference.

“I don’t know where we would be without those therapists, early intervention, AutismUp, CP Rochester, all these amazing people who every day are working with Vivian,” said Sievers. “The therapists and the teachers that she has are just the best, and I do not know where we would be without them.”

But some families do go without.

While Rochester is better than most at providing for families of children with autism, there remain strong ties between social and economic capital and access to help. Low-income and minority families are often isolated by geographic location and information disparities, as well as lacking the time it takes to effectively self-advocate.

That disparity was identified by AIR-B, a national autism research network, who described Rochester as a community where “race, ethnicity, and socioeconomic status have been associated with a delay in the diagnosis of ASD and access to services.”

Now, steps are being taken to close the divide and to make Rochester’s excellent support programs accessible to more families, not just those with greater means to access them.

Agencies who had previously focused attention on the suburbs are looking to put services on the ground in the city, prompted in part by the high-profile death of autistic Rochester teen Trevyon Rowe, whose body was recovered from the Genesee River in early March.

Tradition of autism care

The clinical work being done at the University of Rochester Medical Center gives Rochester families access to world-class care, but its point of difference is the community partnerships in the area, between health providers and connected families, as well as a powerful support system developed by parents, for parents.

“Families of children with autism and self-advocates have really pushed the national agenda,” said Susan Hyman, chief of developmental and behavioral pediatrics at UR Medicine’s Golisano Children’s Hospital. “The Rochester community has a tradition of collaboration with the university in a very effective fashion, so we have a novel and collaborative interaction that really enhances the seamless service delivery.”

URMC is one of 13 sites across North America, and the only site in New York that’s a member of the nationwide Autism Treatment Network (ATN).

Dennis Kuo, an associate professor and division chief in general pediatrics at the University at Buffalo, said that ATN sites are special because of the multidisciplinary and coordinated approach they take to care. “Children with autism live in the community and require a range of services — medical, education, financial and legal, to name a few. The interventions are best delivered when the professionals and families are working together,” said Kuo. “There are a lot of terrific providers that deliver great care and don’t necessarily know about the fantastic and important work going on next door.”

Kuo’s research focuses on health care systems and how to effectively deliver services that often exist in silos.

“Having an ATN site in Rochester ensures the latest updates in autism treatment are both offered and delivered effectively,” he said. “The ATN’s approach is to break these silos down.”

‘Too big for one person’

Brady said that one of the greatest benefits she's found since moving to the area is in the relationships she's formed with other parents of children with autism, who she said she's been able to connect with through AutismUp, a local organization that started as a small group of moms in 2004.

AutismUp has since expanded to become the leading 501(c)3 autism support organization in the greater Rochester area with more than 2,000 family members.

"AutismUp was a huge part of what made me feel comfortable moving (to Rochester)," said Brady. "When my son was diagnosed, I asked our pediatrician (in Florida) if there was a parents' group, and he said that there had been one, but it kind of petered out, and then he just kind of sent me home with pamphlets."

Rochester was different.

"There's an (AutismUp) Facebook group for parents where you can ask questions, and the people you're asking are people who have gone through the same thing that you're going through," said Brady.

Like Brady, Sievers said the support his family has found through AutismUp has made a world of difference.

"There was a year when (Vivian) was two or three where we just kind of felt lost. We were asking questions to therapists that they legally or ethically couldn't answer because they aren't doctors who diagnose," said Sievers. "But your fellow parent who has been through it can tell you their experiences."

"My biggest regret is I didn't get connected with AutismUp as soon as I got here," said Sievers. "I like to do things on my own, but this is just too big for one person, for one family to handle."

'A major gap'

While the Brady and Sievers families and others like them have found unparalleled support since relocating to the area, other families in Rochester continue to face a host of obstacles that keep them from accessing the worldclass care available through URMC and other providers, including inadequate insurance and transportation and difficulty scheduling.

In areas where access to services is limited — for instance, Early Intervention, where there is a major shortage of qualified providers — families with the means to pursue assistance aggressively are much more likely to be served than poorer families.

"Social and economic status has a huge impact on a family's ability to get services for their kids," said Dan DeMarle, who owns Rochester-based DeMarle Inc., which provides various care specific to developmental delays. "If I'm a parent working two jobs, 14 hours a day, then I have no time to try and pursue outside-of-school supports or learn about them."

Most important, though, might be a lack of information about what opportunities exist. "There's a major gap in communication," said Walida Monroe-Sims, the mother of an autistic son in Rochester. "Parents don't even know. ... It was sad, in Trevyan's case, that it's just now with his death you see these organizations coming in. Like, where were these people?"

Clara Washington, a single mother who lives in Rochester's 19th Ward, said that before her daughter Jayla, now 7, was diagnosed as autistic, she didn't really understand what autism was.

"For four years after Jayla was born, I had been telling people that I knew something was different about her, because I have a 17-year-old son and the growth was totally different. I just didn't know what it was," said Washington. "If you looked at her, she looked like the typical child, but if you spent time with her you'd realize she was different."

Through a recommendation, Washington scheduled an evaluation for her daughter. It was a year before she was able to secure an appointment.

“I worked for a pediatric doctor’s office before, so I asked lots of questions when I heard certain things, but a lot of people aren’t in the position that I’m in because I worked in a medical office,” said Washington. “They don’t know the questions to ask. That’s the problem.”

Washington said that her case was unique, in that she was put in touch with AutismUp immediately after her daughter’s diagnosis. She said the organization was invaluable in helping her to understand both Jayla’s diagnosis and the supports available to her, but that she was lucky.

“I was connected, but there’s a lot of parents in the city that just don’t have an understanding of what’s going on with their child and so they just keep waiting — thinking it’s going to be OK,” said Washington. “Without that diagnosis, I wouldn’t have found AutismUp and then I wouldn’t have known how to fight for my daughter’s therapies, because it has been a fight.”

“The doctors don’t tell you that stuff,” said Washington. “The greatest thing that AutismUp has given me is knowledge, but there’s a lot of time that went by where my child could have been learning. I wish I would have known sooner.”

Beyond disparities in information, poor families in Rochester suffer from long-standing inequities in access to the minimum standard of care mandated by federal law and disparities in how special needs students are classified through school.

The Rochester City School District may be the worst in the United States in terms of educating its children with disabilities. It spent more than 20 years under a federal consent decree and faces the prospect of another.

The reason, in part, is that the district has a much greater concentration of those students than either suburban or charter schools. RCSD educates about 25 percent of Monroe County children, but 39 percent of those living with disabilities.

Even within those numbers, racial gaps are evident — white children in RCSD are classified with autism at about twice the rate of black children, who are much more likely to be counted under the catch-all category of “other health impairment.”

Renee Turner, the district’s liaison to its Special Education Parent Advisory Council, is working to build connections with local agencies so that city families can be informed of both medical and social opportunities for their children with disabilities, including autism.

She recalled seeing a story on television about an educational seminar for families of children with disabilities; nearly all the parents and children it showed were white.

“It’s just like anything else – people have to feel welcome,” she said. “It was just phenomenal what they did for Trevyan, the services they provided for him and the support for the family. If there were more outreach with all these organizations, I don’t think they’d be opposed to involving any child that has a disability.”

Closing the gap in autism supports

In late April, AutismUp announced an urgent initiative to fast-track the hiring of a family navigator who will be focused on helping families in the city of Rochester connect with the services already being accessed by their suburban peers.

Once filled, the position will include an office in the Boys & Girls Club of Rochester at 500 Genesee St., and will work to help families navigate the state and school systems, as well as connect parents of children with autism with community partners.

While the implementation of the position had already been in the works, it was originally going to be timed with the opening of the Golisano Autism Center (GAC) in 2019. Organizers said addressing the needs of families in the city can’t wait.

“Everything to come out of Trevyan’s death solidifies the importance of us opening the Golisano Autism Center within the city of Rochester and the importance of making sure everybody has access,” said Sarah Milko, executive director of AutismUp. “This is about how this community responds in the wake of need.”

The \$5 million center is funded in part through the support of the Golisano Foundation. The effort comes through the partnership of three local agencies — Al Sigl Community of Agencies, AutismUp and CP Rochester — and will serve as the new home to the current services offered by the organizations, and others, in one a shared space.

“We are proud to support this important new center, which will create the first-ever central location in our region where people with autism and their families may access comprehensive, coordinated services from multiple providers all under one roof,” said Ann Costello, executive director of the Golisano Foundation.

In addition to creating greater awareness about available support, the GAC’s South Avenue location will allow families in the city access to recreational services that they miss out on at AutismUp’s current location in Webster.

“I want Jayla to go there (to AutismUp) so badly, and we get out there every now and again because I do have transportation,” Washington said.

“But, there are certain programs they have that we can’t get to because they start at 5:30 p.m. and I don’t get out of work until 5 p.m., so to drive out there from the city... it’s just not going to work.”

“We don’t have any facility like that right now in the city dedicated to children on the spectrum.”

Hyman said the GAC will change that, noting that what medical providers and parents hope for is that their children will grow into adults who are employed, have jobs they like, have active leisure so they can maintain wellness both emotionally and physically, and have appropriate independence where they live.

“This is what we want for all of our children, whether or not they have autism,” said Hyman. “The Golisano Autism Center’s attention to education, leisure and transition to adulthood in non-medical areas really complements the work we do at the medical center, and will be central for Monroe County to make those services more accessible than before.”

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Melissa and Chris Sievers play with their daughter, Vivian, at their Pittsford home. The Sievers moved from Maryland, in part, to access more early childhood services for Vivian, who has autism. MAX SCHULTE/@MAXROCPHOTO/STAFF PHOTOGRAPHER



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