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UPCLOSE

Gretchen Jacobs, lobbyist — Parent of autistic child pushes for treatment funds

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Autism, which usually strikes before the age of 3, is a neuro-developmental disorder, characterized by impaired social interaction, impaired communication and restricted and repetitive interests and activities. On average, it occurs once in 400 births for boys, but one in 150 births for girls according to the Center for Disease Control and Prevention.

The causes are debated, there is no cure, but treatment experts say early intervention has resulted in 39 percent recovery, which means the children become indistinguishable from their peers, they test within normal ranges and have the ability to make friends.

In the past, the Legislature has funded the Southwest Autism Research and Resource Center (SARRC), and a bill sponsored last year by Sen. Carolyn Allen, R-8, provides \$7.1 million for research at Translational Geonomics Research Institute into early detection of autism.

Currently, the state is in a three-year pilot program at \$1.8 million per year that brings in the California-based Center for Autism and Related Disorders (CARD) to provide services, which are expected to begin next week. CARD is funded under H2371, which also provides \$200,000 for the training of other providers, as well. The contract with CARD has caused some grumblings, misunderstandings and inaccurate publicity, says lobbyist Gretchen Jacobs of Greenberg Traurig, who pushed for the pilot program with CARD.

She and her husband are the parents of a 14-month old autistic girl. They have spent a "substantial" amount of money for her care, she said in an April 25 interview, adding that her daughter is not in the pilot program. "It has been a huge burden financially," she said.

Ballpark?

It was substantial. My husband wants me to be very low profile about her, other than she regressed. She was doing very well and developing normally and then she became, I think, very severely autistic.

At what age?

14 months. My older daughter was diagnosed in the same week that I gave birth to my younger daughter. It was quite a week. I had her evaluated four times. My husband says I have evaluation mania.

Let me play devil's advocate . . . Your position of influence as a lobbyist — had you not been in that position, do you think you'd have been able to get the \$1.8 million in the appropriations bill?

I think the reason it was put in was because people know that I am an honest person. I don't see it as a lobbyist. I really credit the Legislature. I know I'm getting a lot of credit for this, but I really credit the Legislature and the governor. It's a very timely issue, and CARD's reputation is world-renown. Whether you are king of a country or a celebrity, if you have a child with autism, they are being treated by CARD. To have CARD come to Arizona is one of the biggest things to happen in autism.

So, you think this whole competitive thing will work out — that's its best to have more than one outlet?

Oh, my, yes. You get CARD here and SARRC with the new person they've got, and it only helps the state. Competition is good, especially when it comes to meeting these needs.

Any federal help here?

Yes, that's what I will be eligible for, Arizona long-term care paid for by the federal government. I failed to fill out the paperwork, but I am getting around to it. If autism is untreated, it is debilitating. Most people who do not receive treatment are fully dependent for the rest of their lives.

Do they live a normal lifespan?

Yes.

So, for her lifespan, you're looking at millions.

Yes. With early intervention, they have a long history of success.

Is your child on any medications?

No.

Is this [state funding] at all gotten political?

I think there was a misunderstanding originally that this was a three-year pilot program. There were some providers who wanted to make sure this wasn't a long-term commitment by the Legislature to permanently fund CARD.

But, do you think it will go beyond that?

I think after [the three years] there will be a legislative study committee. I think that the CARD program will show such dramatic results that there will be a lot of attention paid to how important and exciting early treatment can be.

Does not the state need to continue to provide help?

Yes, and I think there will be a big assessment done as to what needs to be done next: Is there a way to do it more cost efficiently, and how can other providers provide services in other areas of the state?

\$1.8 million doesn't seem like very much.

I think of it as when you have the opportunity to save the life of a child and their family, it's a pretty major impact. The cost per child is small compared to the lifetime care and the emotional pull it can have on a family. I recognize there are a lot of other needs in the state.

There has to be thousands of families that won't get into the program.

It has to be first-come, first-served. As soon as a child is diagnosed, they have to get qualified through the Department of Disabilities. I was turned away from several organizations originally because we [the organizations] need to go through DDD so we can get paid. And they refused to accept private payment, which I thought was really interesting. I'm qualified for DDD . . . I think most people, regardless of income, have the state pay for their treatment.

So, someone is home with your daughter all day?

Yes. Most people don't have the means to be home all day with their child while they receive therapy. I was motivated by how challenging it was for me, dealing with all the emotional and financial support I had. I couldn't imagine what other people are going through that don't have all that. And that's what really spurred me on. I was flying therapists in from California from CART and I thought it shouldn't be that, because I am able to I can have this kind of care that other people in Arizona don't have access to and that's what really pushed me to work so hard for this. I have done this pro bono, and CARD is not a client of the firm and neither is SARRC. I'm doing this as a mother, not as a lobbyist. This should be a story about the Legislature and the governor. They really stepped up.

Up Closer

Gretchen Jacobs maintained her own lobbying firm where she worked extensively with the Legislature and regulatory agencies before joining Greenberg Traurig, an international law firm. Prior to establishing her practice in government relations and regulatory law, she represented corporate clients in civil court in the fields of high tech, insurance and health care.

In an interview published in Arizona Capitol Times last year, she highlighted two professional accomplishments: "Working with legislators and the governor, who increased the availability of quality, trained therapists to work with children with autism; and working with legislators who privatized all of the state agencies' telecommunications onto one converged network for voice, video and data."

Ms. Jacobs said she got into public policy because "every issue of importance in the state is discussed and evaluated during the Legislative session." She continues: "At the Capitol, effective advocacy for my clients means considering the broader issues. Every legislator I work with and the governor consider first of all — is this legislation in the best interest of the state?" Ms. Jacobs worries about how the state will cope with growth.

Her advice to other women interested in public service and/or politics was: "Make sure you love what you do because your workday does not end at 5."