

Many parents of kids with autism don't put faith in pediatricians

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Researchers say pediatricians also don't feel knowledgeable enough to guide families on treatments.

(HealthDay) -- Many parents of children with an autism spectrum disorder don't feel they can turn to their pediatricians for advice on treatments, a new study finds.

Likewise, many pediatricians don't think they have the knowledge -- or time -- to devote to children with autism, with some citing reimbursement policies that don't allow for payment for lengthier appointments or for managing complex cases.

The pediatricians interviewed for the study also said they felt especially uncomfortable advising [parents](#) on [alternative therapies](#), which are commonly used by families with [autistic children](#).

"Most parents are not going to pediatricians with questions about treatments. They looked to them for referrals to specialists or to community resources, but they really weren't going to them for guidance about what sort of treatments they should pursue," said study author Dr. Susan Levy, who directs the Regional Autism Center and the Center for Autism Research at Children's Hospital of Philadelphia.

"And the pediatricians didn't feel informed enough to make those recommendations," she added.

Autism experts said the findings point to a problem that needs a solution.

"This study validates what previous studies and parents have told us: Many pediatricians are not prepared to provide the kind of advice and information that parents need after receiving a diagnosis of autism for their child," said Geraldine Dawson, chief science officer for Autism Speaks.

She added: "Without advice and information from their primary care provider, families must navigate treatment options on their own, which can be confusing and complex. This adds to the already high [levels of stress](#) that families are experiencing. We need greater emphasis on autism training for [primary care physicians](#) so they can help parents make informed decisions about their child's care."

The research, to be presented Wednesday at the International Meeting for [Autism Research](#) in Toronto, involved interviews with 20 parents of children aged 3 to 5 with an [autism spectrum disorder](#) and 20 pediatricians affiliated with Children's Hospital.

Ideally, pediatricians would do more than refer patients elsewhere, Levy said. They would serve as a "medical home," managing all aspects of the child's care, receiving reports, consulting with specialists and helping

parents integrate autism treatments with the child's overall development and health needs.

Key to this arrangement is shared decision-making, in which pediatricians advise parents on, say, the evidence available about alternative treatments, and together parents and doctors decide the best course of action, she added.

In reality, that's rarely what happens, Levy said. "What the pediatricians should do and what they think they should do is very different from what actually happens," she said.

Many families, for example, turn to alternative treatments to help with autism, since there aren't any medications that treat the core symptoms of autism.

But many doctors find it difficult to frankly discuss those treatments with parents, because there is little evidence that they work even though some parents think they do, Levy said.

"Complementary and alternative medicine was an area pediatricians mentioned frequently as an area of discomfort. They knew they wanted to protect families from harm and figure out how to communicate risk and evidence," Levy said.

Parents, on the other hand, perceived pediatricians as frequently dismissive or negative toward alternative therapy, and so often didn't bother to bring it up, the study showed.

Families also said pediatricians offered little support to them in dealing with the stress of [autism](#), and that instead they turned to friends, family or other community resources.

Because this study was presented at a medical meeting, the data and conclusions should be viewed as preliminary until published in a peer-reviewed journal.

More information: The [National Institutes of Health](#) has more on autism.

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