



The Medical Home for Children With Autism Spectrum Disorder

What is a *medical home*?

Parents, pediatricians, and other health care professionals are encouraged to work together so that all of the needs of children and youths are met. This partnership is at the core of what the American Academy of Pediatrics (AAP) calls a *medical home*. The medical home is not a physical place but rather a way of giving a child comprehensive and compassionate primary care. A medical home helps coordinate the medical care and other services your child needs into a single plan for your child's health. The AAP and other medical organizations support the idea of the medical home as an important part of caring for children with lifelong conditions. This is because the approach has been shown to help children. It is important for families and doctors to feel as if they are partners in the care of the child.

Why is it important to have a medical home?

Studies have shown that having a family-centered medical home leads to better treatment. In a family-centered medical home, the pediatrician communicates with the family to be sure that regular care is achieved, such as immunizations and other preventive activities. Your child's pediatrician helps organize and coordinate care for your child's autism spectrum disorder (ASD) and any other long-term conditions she may have.

Many children and teens with ASD see a variety of specialists to manage certain medical conditions. Your child's pediatrician and these specialists can give your child the best care when they communicate with each other and are able to have their suggestions put into an overall plan for your child's health and wellness. A medical home can help provide this support.

Families who receive care in a medical home are also more likely to be connected with community agencies and services. This way they can receive more support from agencies and from other families in similar situations. Children are more likely to receive services and treatments that the pediatrician or specialist has recommended when they receive care in a medical home.

What is a *care plan*?

The child's primary care team plays an important role in your child's and family's life. They may work together with you to create a written *care plan* for your child. A care plan includes educational services, therapies, medical issues, family supports, and emergency crisis plans. A care plan is the same as the treatment plans developed by your child's school, speech therapist, or other specialists. A care plan includes all these aspects of your child's care, and it also finds ways that doctors and agencies can work together on common goals. While a care plan cannot solve every issue, it does ensure that all your child's needs are identified and addressed as much as possible.

If you think that your child needs a written care plan, ask your child's pediatrician about making one. Often, pediatricians work with nurses or care coordinators to make this kind of plan.

What is a *care notebook*?

Care notebooks are used to track your child's ongoing care and services—for example, which doctors were seen, why, and when. They can help families communicate with doctors. They serve as a place to write down questions or concerns to bring up with a doctor or a way to share information from one doctor to another. You can bring your child's care notebook with you to all appointments and on all trips. This keeps doctors up-to-date and allows them to have information in case of emergency.

There are many different ways to develop your child's care notebook (see the Resources section on page 2).

How can I make my child's medical home successful?

Medical home visits may take a little longer, because your care team needs to identify and address all the issues with your child and your family. Try to make appointments that are long enough to discuss your concerns. You may need to have frequent follow-up visits to make sure that care stays up-to-date.



How can I make my child's medical home successful? (continued)

You need to let the office know that you have extra questions so that they can schedule enough time. Bringing toys, snacks, or another adult to appointments is very helpful. It is also helpful to schedule your child as the first or last patient of the day. If you are worried about discussing issues in front of your child or if you are worried that your child's behavior will make it hard to have a good discussion with the pediatrician, you can ask about scheduling a visit without your child or about having a telephone or video visit. Also, if something changes, it is important to let your child's pediatrician know so that she can help.

Another important aspect of the medical home is giving compassionate care that meets your family's social and cultural needs. Tell your child's pediatrician a little about how your family works. Let him know about any language, cultural, or religious needs and about all the care that your child gets. This includes complementary and integrative care or care provided through your culture or religion. Your child's pediatrician will give you the best advice if he understands your family's needs. If you are feeling confused or uncomfortable, let the pediatrician know so that he can help you.

You know your child best, and over time, you will become an expert on your child's condition. Parents' knowledge and opinions are recognized and respected in the medical home. Be sure to seek information, ask questions, and trust your feelings.

Resources

American Academy of Pediatrics HealthyChildren.org: www.HealthyChildren.org. This is the official AAP website for parents.

Autism Speaks "Resource Guide": www.autismspeaks.org/community/fsdb/search.php. This resource guide links families to a variety of resources and contact information in their own communities. Families can enter their state to identify services such as early intervention, applied behavioral analysis, health care professionals, dentists, and respite care.

Family Voices: www.familyvoices.org. There is a "Find Resources in Your State" feature at the bottom of the home page, where families can identify the Family Voices organization in their state and available family-to-family activities, such as parent-to-parent groups and conferences.

National Resource Center for Patient/Family-Centered Medical Home: www.medicalhomeinfo.org. This resource is for health care professionals, families, and anyone interested in creating a medical home for all children and youths. The website has information for families and professionals. Of special interest and use to families are "Building Your Care Notebook" and "Medical Home Videos for Families" in the For Families and Caregivers portion of Tools & Resources.

