



The Medical Home for Children With Autism Spectrum Disorders

What is a medical home?

Parents, pediatricians, and other health care professionals are encouraged to work together so that all of the medical and nonmedical needs of children and youth are met. This partnership is at the core of what the American Academy of Pediatrics (AAP) calls the *medical home*. Medical home is an approach primary care practices can use to provide comprehensive and compassionate care. This approach helps coordinate the medical care and other services your child needs into an integrated overall plan for your child's health. Because of the effectiveness of this approach and the benefits that patients receive under this care model, the AAP and other medical organizations have endorsed the medical home as an important part of caring for individuals with lifelong conditions. It is important for families and clinicians to feel like they have a constructive partnership for the care of the child.

Why is it important to have a medical home?

Studies have shown that the presence of a family-centered medical home leads to more effective treatment of conditions. In a family-centered medical home, the pediatrician maintains patterns of communication with the family that help ensure routine care is achieved, such as immunizations and other preventive activities.

Many children and adolescents with autism spectrum disorders (ASDs) see a variety of specialists, such as developmental and behavioral pediatricians, neurologists, and gastroenterologists, to manage certain medical conditions. Your child's pediatrician and these specialists can provide your child with the best and most efficient care when they communicate with each other and are able to have their recommendations integrated into an overall plan for your child's health and wellness. A medical home can help provide this support.

Families are also more likely to be effectively connected with community agencies and services and receive more support from such agencies as well as from other families in similar situations. Children are more likely to receive services and treatments that the pediatrician or specialty practitioner has recommended.

What is our child's care plan?

The medical home primary care practice team plays an important role in the child and family's life and will work together with parents to create a written care plan for each child. A *care plan* includes the child's treatment plan, which is made up of educational services, therapies, medical issues, family supports, and emergency crisis plans. A care plan is not a substitute for the treatment plans developed by your child's school, speech therapist, or other involved professionals or agencies. A care plan includes all of these aspects of your child's care and identifies ways in which clinicians and agencies can work together on common goals. While a care plan cannot guarantee that every issue will receive all treatment or support needed, it does help ensure all of your child's needs are identified and addressed as much as possible.

What is our child's care notebook?

Care notebooks can be used to track your child's ongoing care and services—who was seen for what purpose and when, and so on. They also are valuable in helping families communicate with various doctors by serving as a ready place to write down questions or concerns to bring up with a doctor, or information to transmit from one doctor to another. It is recommended that families bring their child's care notebook with them to all appointments and on all trips to keep doctors up to date as well as to have information available in case of emergency.

There are many different ways to develop your child's care notebook (see Resources).

How do visits to the medical home work?

Visits to your child's medical home may take a little longer to identify and address all the issues pertinent to your child and family situation. Parents and the medical home care team should schedule appointments that are long enough to discuss all of their concerns. You need to let the office know that you have additional questions so they can schedule enough time. Bringing toys, snacks, or another adult to appointments is often very helpful. Parents know their child best and over time, they often become experts concerning their child's disability. Parental knowledge and opinions are recognized and respected in the medical home. Parents are encouraged to seek information, ask questions, and trust in their intuition.

Resources

American Academy of Pediatrics HealthyChildren.org:
www.HealthyChildren.org

Autism Speaks Family Services 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 zip code and a range from 5 to 500 miles away to identify services such as early intervention, applied behavior analysis, health care practitioners, dentists, and respite care.

Family Voices: www.familyvoices.org/states. From this site 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 Center for Medical Home Implementation: www.medicalhomeinfo.org. This resource is for health professionals, families, and anyone interested in creating a medical home for all children and youth. The Web site has information for families and professionals. Of special interest and use to families are "Building Your Care Notebook" (www.medicalhomeinfo.org/for_families/care_notebook) and "How to Partner With Your Physician" (www.medicalhomeinfo.org/for_families/partner_with_physician.aspx).

The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate. Original document included as part of *Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*, 2nd Edition. Copyright © 2013 American Academy of Pediatrics. All Rights Reserved. The American Academy of Pediatrics does not review or endorse any modifications made to this document and in no event shall the AAP be liable for any such changes.

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