



Autism Society
of NORTH CAROLINA



Autism & Health

Getting the most out of your health care

Partners:

NC Council on Developmental Disabilities

Easter Seals UCP NC

The Arc of NC

University of North Carolina at Chapel Hill,
Department of Allied Health Sciences and Carolina Institute for Developmental Disabilities

HRSA grant #H6MMC26248

Rev.01.17

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About the toolkit

For individuals with autism and their caregivers, going to the doctor can be a stressful situation. Individuals may not be able to communicate about health problems they are experiencing. Even if they are healthy, they may be anxious about the unfamiliar experience of going to a doctor and undergoing procedures. This toolkit is designed to help improve these experiences. The toolkit will help individuals and caregivers organize their health information, share important information with their health-care provider, and prepare for appointments.

The toolkit also provides information about the benefits of a medical home, where a primary care provider knows your family and health history. A medical home is a family-centered, team-based approach to providing comprehensive health care for children and adults. A medical home can improve the health and well-being of the individual with a disability and reduce the stress on families and other caregivers.

Beyond the toolkit

If you would like help in finding and navigating health care for an individual with autism, ASNC can help. In every NC county, ASNC has Autism Resource Specialists who are experienced parents of children with autism and trained autism advocates. You can find contact information for the Autism Resource Specialist in your community here: www.autismsociety-nc.org/resourcespecialists. ASNC also offers workshops that might be helpful; you can find the workshop schedule at www.autismsociety-nc.org/workshops or ask your Autism Resource Specialist.

The ASNC Resource Directory, at www.referweb.net/asnc, can provide a list of health care providers in your community. The developing, online database is searchable by category, keyword, and agency name.

ASNC's local chapters across North Carolina are also an excellent place to connect with other families, ask for recommendations, and learn from their experiences. Chapters are volunteer-run and offer support and education on a wide variety of topics. To find one near you, please go to our website: www.autismsociety-nc.org/chapters.

If you would like to read more, please refer to the end of the toolkit for additional information sources that are recommended by the ASNC Advocacy, Clinical, and Bookstore staff. To keep updated on the latest books and DVDs, we invite you to connect with the ASNC Bookstore on Facebook, at www.facebook.com/AutismBookstore, or by emailing staff at books@autismsociety-nc.org to tell them you would like to join the newsletter mailing list.

In addition, ASNC offers an array of services for your loved one. Please visit www.autismsociety-nc.org to learn what is available in your area.

Taking Autism to the Doctor

Going to the doctor can be a very stressful experience for people with Autism Spectrum Disorder (ASD) and their caregivers. Possible challenges include:

- anxiety about what will happen
- unstructured time in the waiting room
- sensory issues
- other patients present
- fear of separating from caregiver
- unfamiliarity with the office, office staff, procedures, and equipment
- negative experiences from the past and associations with pain

As a caregiver, you can take steps to ease individual office visits for patients with autism, yourself, and medical professionals. Planning ahead is key: prepare the doctors and staff for your loved one, and prepare your loved one for the doctors and health-care staff.

If you are looking for an autism-friendly medical home or physician, ask other parents for recommendations. Visit the ASNC website www.autismsociety-nc.org to contact your local ASNC Chapter; they often have a Facebook page or email group where you can ask for a recommendation. You can also consult your local Autism Resource Specialists. Additionally, use the ASNC Resource Directory for a list of practices in your community.

Prepare yourself, the caregiver

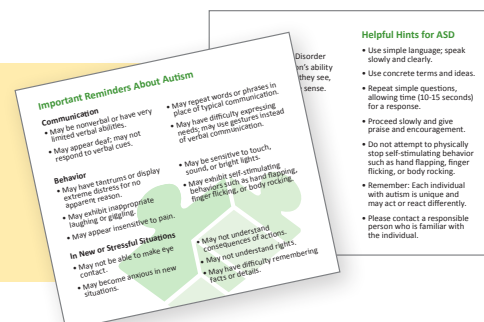
- Arrange to visit the office so you know how to plan.
- Look for situations that might present challenges, e.g. elevators, the waiting room, and sensory issues such as smells, noises, or lighting.
- Ask what tests and procedures to expect at the visit, e.g. blood work or shots.
- Ask whether videos or pictures of exam rooms and procedures are available. If not, ask to take photos to prepare your loved one.
- Decide whether a “practice” visit to the office would increase or decrease anxiety.
- Complete any paperwork prior to the appointment, e.g. insurance verification, release of information, and even pre-payment.
- Give the office any forms you need filled out, e.g. school or camp forms, insurance forms.
- Provide any assessments or records that might be helpful, e.g. psychological reports
- Create a health-care notebook to document your visits, including the names of all providers, medications, interventions, etc. For customizable documents that make up a health-care notebook, visit the American Academy of Pediatrics at <https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx>.
- Identify your top three “most important issues” for the day’s visit and ask for help addressing these concerns.

ASNC staff provide workshops for medical and health care providers as well as for family members on "Taking Autism to the Doctor." Find your local Autism Resource Specialist at www.autismsociety-nc.org/resourcespecialists. for more information.

Prepare the health-care staff

- Explain that your goal is to make the visit successful for your child and the staff. ("Child" in this section refers to dependents of any age.)
- Ask whether any staff member is particularly comfortable or knowledgeable about autism.
- Ask the staff for the best time to schedule an appointment to avoid a wait and tell them why this is important for your child.
- Identify a quiet or separate waiting area in case your child gets upset.
- Arrange for extra time for the appointment if needed.
- If there is a procedure that you know will cause a meltdown, ask how essential it is and whether it can be eliminated or done at home. Examples might include taking the temperature or blood pressure.
- For invasive procedures, discuss whether some level of sedation is appropriate.
- Ask the staff for the best way to provide information about your child in advance of the visit. Is it through a conversation with a staff member, an email, written documents for the chart, or an online patient portal?
- Make a written list of your medical concerns for the visit and ask that it be attached to your child's medical record.
- Prepare a brief patient information sheet about your child, including interest and strengths, possible triggers and challenges, sensory issues, and behavior and communication strategies that work. (See appendices)
- Ask that the patient information sheet be attached to your child's medical record.
- Keep a copy for your records and bring it with you to your appointment.
- Bring your medications, including vitamins, supplements, and over-the-counter medicines that your child is taking and the dosages. Check whether you need a refill.
- If you have recent behavioral concerns, make a list of all the changes that you and others have observed.
- Bring a video of your child's unusual behaviors or movements, if you have one. A cell phone video can capture new behaviors of concern and can be even be emailed in advance of the visit.

ASNC has small "Helpful Hints" cards that give a brief explanation of autism and can be handed out to the public. These may be useful in the waiting room or for the office staff. Send an email to info@autismsociety-nc.org to request cards.



Prepare your loved one

1. Help your loved one understand what to expect at the visit

- Provide visual supports to clarify what will happen, such as a picture schedule, written schedule, or electronic schedule. (See appendices)
- Mark the visit on the calendar if used for visual support.
- Develop a social story on what to expect during the visit. (See appendices)
- Read a book on going to the doctor. (See resource list)
- Practice “pretend” medical procedures at home.
- Create a toy doctor’s kit to help familiarize the individual with the equipment and what to expect.
- Demonstrate on others or on toys what will happen during a physical examination or procedures.

2. Teach calming strategies beforehand

- Deep breathing
- Counting
- Singing songs
- Talking about a favorite interest
- Stress and fidget toys
- Walking and pacing
- Deep pressure
- Favorite books and toys
- Headphones and ear plugs

3. Bring preferred activities for comfort and distraction

4. Bring an autism toolbox with you.

Include medications, your visual communication system, calming toys, fidget toys, change of clothes, headphones, music, snacks, etc.



I want to see a
medical provider
who respects me
and will be around
for a while.

Adult with a Disability

During the appointment

- Once you arrive, remind the office staff that your loved one has autism and mention the plans you made with them for the visit.
- Bring a support person with you to take notes or assist you during visit.
- Be prepared with distractions.
- Explain what is happening.
- Give choices whenever possible, e.g stand on scale or take temperature.
- Focus on the reward.
- Resist telling any white lies, such as “this won’t hurt.”
- Use timers and clocks and to show a definite end.

Medical Home



American Academy of Pediatrics illustration

What is a medical home?

A medical home, also known as a patient-centered medical home, is a model of care or type of doctor's practice that uses a family-centered, team-based approach to providing coordinated, comprehensive health care for children and adults. The medical home can treat acute illness, provide ongoing routine care, support a healthy lifestyle, and coordinate care with other medical and health-care specialists and with community services.

Having a medical home means patients and families receive a high level of quality health care with their doctor's office. It means not only having a "place" such as a pediatrician or primary care doctor's office, but also a well-prepared health-care staff and a strong, trusting relationship among clinicians, staff, patients, and families.

A medical home is:

- **Accessible:** You can access services with shorter waiting times, "after-hours" care, 24/7 electronic or telephone access, and use technology to improve communication.
- **Family-Centered:** The critical role of the family is recognized and supported. The individual, family, and provider share the responsibility in decision-making. The medical home offers patient and families full participation in their care.
- **Continuous:** Care is provided over an extended period of time to ensure continuity. Transitions, including those to specialists and into the adult health-care system, are planned and organized with the patient and family.

— “ —

I want my daughter to go to a practice that respects us, where the staff know my child, and appreciate her.

Mother

— “ —

What my family needs is openness, respect, relationships, leadership that sets the right tone, sense of humor, quiet space, and longer appointments when necessary.

Parent

- **Comprehensive:** A personal physician and team can provide sick care and well care, and referrals to specialty care and community services. The team may include physicians, advanced practice nurses, physician assistants, nurses, pharmacists, nutritionists, and social workers. The medical practice is knowledgeable about community resources and seeks out information.
- **Coordinated:** The individual and family are linked to specialists and community-based services. The medical home works as an organized team and sees the community as an asset.
- **Compassionate:** Concern is expressed and demonstrated in all encounters by all staff. Appointments are scheduled with the consideration of individual and family needs.
- **Culturally effective:** Cultural background is recognized, valued, and respected. Staff is sensitive to stereotypes and the importance of language and communication.

What are the benefits of a medical home?

- Knowing where to go for care
- More organized care
- Support from a team of informed health-care professionals who know their patients and take responsibility for their ongoing care
- More efficient communication – families and individuals do not have to continually repeat information to multiple providers
- Appointments scheduled in a coordinated, efficient way to avoid duplicated services
- Comprehensive, central health record that contains all pertinent information
- Reduced family stress
- Increased family satisfaction with health care



We all benefit from having a medical provider who knows us, our health history and habits, and who can recognize changes in our health.”

Parent

Where do I find a medical home?

A number of national organizations offer recognition to practices that have earned the designation of a patient-centered medical home. Becoming accredited is one way a primary care practice demonstrates a commitment to ongoing improvement.

For patients and families who receive Medicaid or Health Choice: Once enrolled in these programs, the doctor’s practice you choose is your primary care provider and your medical home. This information is listed on your Medicaid or Health Choice ID card. You may choose any doctor who accepts Medicaid or Health Choice patients to be your primary care provider and medical home. Your county Division of Social Services (DSS) caseworker will help you choose a primary care provider or help you to change, if needed.

You may also want to talk with your DSS Caseworker about choosing a doctor who belongs to the Community Care of North Carolina/Carolina ACCESS (CCNC) program. CCNC has regional networks of clinicians and health care organizations

who work within a medical home model for children and adults. Through CCNC, you can ask for a care manager to help you understand and manage your health care concerns.

For more information, visit <https://dma.ncdhhs.gov/medicaid/get-started/doctor-and-medical-home>.

For patients and families with private insurance: Private payors and insurers are also supportive of patient-centered medical homes. For example, BCBSNC has an incentive program to support independent primary care practices in achieving PCMH recognition. Contact your health-care insurer for more information. If you are interested in receiving care in a medical home, ask your insurer whether there are medical homes available to you in your plan network.

For anyone: Federally Qualified Health Centers provide a patient-centered health care home that integrates high quality medical, dental, behavioral health, pharmacy, and enabling services without regard to a person’s ability to pay. Federally Qualified Health Centers (aka Community Health Centers) are geographically dispersed across 74 counties and operate 200 clinical sites. <http://www.ncchca.org/>

What if I am happy with my existing health care?

You may already be receiving good quality care from a medical practice you trust and that embodies the traits that a good medical home should provide. There are still ways you can partner with your doctor's office to assist them in providing quality care to patients and families with special health-care needs.

- Learn more about the medical home approach. Review the resource section of this toolkit.
- Ask your doctor whether the practice has or is considering medical home recognition. (You might be unaware that they are already an accredited medical home.)
- Connect them with an ASNC Autism Resource Specialist for autism education and information on community resources for special-needs families.
- Share your insights and knowledge about autism and special health-care needs from your experience.
- Use the ideas in this toolkit to prepare yourself, your loved one, and the health-care staff for visits.
- Share this toolkit with your primary care provider to share with other families.
- Offer positive feedback on the health care you receive when it is helpful and compassionate.
- Make suggestions for how your health-care experience might be improved.

Resources on medical homes - national

American Academy of Pediatrics, National Center for Medical Home Implementation

www.medicalhomeinfo.org

The American Academy of Pediatrics (AAP) functions as the National Center of Medical Home Initiatives and catalogs medical home efforts across the country. Provides medical home resources, technical assistance, and support to physicians, families, and other medical and non-medical providers who care for children and youth.

Centers for Disease Control and Prevention, "Learn the Signs. Act Early"

www.cdc.gov/ncbddd/actearly/

"Learn the Signs. Act Early." is a federal program aimed at improving early identification of children with autism and other developmental disabilities so children and families can receive the services and supports they need.

Got Transition, Center for Health Care Transition Improvement

www.gottransition.org/youthfamilies/index.cfm

The center works to improve the transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

The National Medical Home Autism Initiative

www.waisman.wisc.edu/nmhai/

National technical assistance, resource and advocacy project designed to improve the capacity of the medical home and early intervention community to identify, appropriately serve and integrate children with autism into their communities.

PACER's Family-to-Family Health Information Center

<http://www.pacer.org/health/medicalhome.asp>

The Family-to-Family Health Information Center (F2F HIC) provides a central source for families of children and young adults with special health care needs and disabilities to obtain support, advocacy, and information about the health care system. PACER promotes family-centered care and family and professional collaboration at all levels of health care.

Resources on medical homes - North Carolina

Community Care of North Carolina

www.communitycarenc.org/

This program forms regional networks of clinicians and health-care organizations to enhance care coordination and delivery of care within a medical home for children and adults.

Exceptional Children's Assistance Center

www.ecac-parentcenter.org/

The Family Health Information Center and Family Voices State Affiliate Organization of North Carolina provides education, information, and peer support to families of children with special health-care needs.

NC Academy of Family Physicians

www.ncafp.com/practice-resources/patient-centered-medical-home/

This professional organization is the policy voice for all family physicians and their patients in North Carolina and works to advance the specialty of family medicine, in order to improve the health of patients, families and communities in our state. .

NC Health Choice for Children

www2.ncdhhs.gov/dma/healthchoice/

The Children's Health Insurance Program of North Carolina provides health insurance to children whose family income is 200% of the federal poverty line.

NC Medicaid

<https://dma.ncdhhs.gov/>

Find information on Medicaid programs, resources, providers, and contacts within North Carolina.

NC Pediatric Society

www.ncpeds.org/

This professional organization provides news, advocacy/legislation information, resources, and opportunities to connect with pediatric experts within North Carolina.

We hope that the information presented in this toolkit helps you and your family get the most out of your health care. Medical visits can be stressful, but with some preparation and a good relationship with your medical provider, these experiences can be improved.

Appendices

Electronic apps

Healthcare Communication enhances communication between patients and caregivers

Pictello helps caregivers make their own social stories

Model Me Going Places includes a social story on going to the doctor

Toca Doctor gives users a chance to play doctor and learn about the human body

Birdhouse - for Autism helps caregivers keep track of records relating to care

Healthier Me by Children's Specialized Hospital reinforces healthier choices and habits

Recommended Books & DVDs

All of these titles are available in the ASNC Bookstore.

Shop online at www.autismbookstore.com to benefit ASNC.

American Medical Association: Boy's Guide to Becoming a Teen

Boys Body Book: Everything You Need to Know

Care and Keeping of You

Care and Keeping of You 2: The Body Book for Older Girls

Eating for Autism

Special Needs Kids Eat Right

Life and Love

DVD: Managing Puberty, Social Challenges, And (Almost) Everything

Picture This: Places You Go/Things You Do (Photo Software on CD-ROM)

Things to Know About Me

Fill out this worksheet and make copies to bring with you to share with health-care staff.

Name: _____ Contact Info: _____

My interests: _____

My strengths: _____

My communication style (e.g. speaking, sign language, assistive device, pictures): _____

My sensory challenges: _____

How you can help me with sensory issues: _____

My behavior challenges: _____










How you can help prevent or minimize behaviors: _____

Sample Schedules

Picture schedule

If your loved one uses a picture schedule, here is an example you could use for a visit to a health-care provider.

My visit to the doctor

 doctor	Go to doctor	
 waiting room	Wait in room	
 listen to music	Listen to music	
 weigh	Take height & weight	
 blood pressure	Take blood pressure	
 wait	Wait to see doctor	
 listen to heart	Exam	
 hello	Say "Goodbye!!"	
 star	Get treat	

Written schedule

1. Drive to doctor's office.
2. Sit in waiting room, reading book or playing iPad.
3. When called, go into back rooms with nurse.
4. Stand on scale to be weighed.
5. Have height measured.
6. Have blood pressure checked with squeezing cuff on arm.
7. Wait for doctor.
8. Do what the doctor says as he or she uses tools to look in your eyes, nose, and mouth and listen to you breathe.
9. Answer any questions the doctor might have.
10. Get a treat.
11. Go home.

Sample Social Story



When I get sick, I go to the doctor. The doctor will help me to get well. The doctor will look in my mouth and in my ears. The doctor will listen to my chest with a stethoscope.



Sometimes I get anxious about seeing the doctor because I don't know what to expect and I don't like being touched. It is okay to feel anxious about seeing the doctor. I can hold my fidget toy or ask for head compressions to help me feel calm. My mom will have a schedule so I know what to expect.



The doctor will know how to help me feel better. When I have finished the visit, I will get a treat. Then I can go home and get well.

About Autism

Autism Spectrum Disorder (ASD) refers to a group of developmental disabilities – including classic autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Syndrome – that affect a person's ability to understand what they see, hear, and otherwise sense. It is a brain disorder that affects communication, social interaction, and behavior.

Individuals with ASD typically have difficulty understanding verbal and nonverbal communication and learning appropriate ways of relating to other people, objects, and events. No two people with ASD are the same. As its name implies, ASD is a spectrum disorder that affects individuals differently and with varying degrees of severity. Additionally, ASD is often found in combination with other disabilities.

It is estimated that up to 1 out of every 68 children has some form of ASD. Evidence suggests that the prevalence rate in North Carolina is even higher than the national average, at 1 in 59. More than 60,000 individuals live with ASD in North Carolina.

The overall incidence of ASD is consistent around the globe, but it is five times more prevalent in boys than in girls. ASD knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of occurrence. While ASD is typically diagnosed in children, it is a lifelong disorder that affects individuals of all ages.

What Causes ASD?

Although it was first identified in 1943, to this day no one knows exactly what causes ASD. However, research to discover its cause is ongoing. Many researchers believe that there is a strong genetic component. Some research suggests a physical problem that affects the parts of the brain that process language and information; other research points to an imbalance of brain chemicals. A variety of possible external or environmental triggers are also being studied. It is possible that ASD is caused by a combination of several factors.

Signs and Symptoms

People with ASD may have problems with social, behavioral, and communication skills. They might repeat behaviors and might not understand change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things.

A person with ASD might:

- have severe language deficits or differences
- talk about or show interest in a restricted range of topics
- not point at objects to show interest, such as an airplane flying over
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- laugh, cry, or show distress for no apparent reason
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- be oversensitive or under-sensitive to pain
- lose skills they once had (for instance, stop saying words they were once using)



Autism Society of NORTH CAROLINA

The Autism Society of North Carolina is the leading statewide resource organization serving people across the autism spectrum throughout their lifespans. We understand the challenges of the autism community because we work with individuals with Autism Spectrum Disorder (ASD) every day.

ASNC works to directly improve the lives of individuals and families affected by autism through advocacy, training and education, and direct services.

Advocacy: We are the only autism-specific advocacy organization in North Carolina, and it is the heart of what we do. We find resources for families, assist with school issues, educate families through workshops, help individuals navigate the services system, and host local support groups. We also give those with autism a voice in public policy by maintaining relationships at the state legislature and other policy-making entities.

Training & Education: We focus on evidence-based best practices that empower self-advocates, families, and professionals. We also work to increase understanding and acceptance of people with ASD in the community.

Services: ASNC is a direct care service provider, and a recipient of the highest level of accreditation by the Council on Quality Leadership for exemplary service provision. Individuals with ASD receive a variety of residential, recreational, vocational, and community-based services that are designed to meet their needs, interests, and strengths.

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facebook.com/AutismSocietyofNorthCarolina
twitter.com/AutismSocietyNC