

Improving Health Care Services

Improving Health Care Services for Autism

<p><u>At the Doctor's Office:</u></p>  <p>Ask your child's doctor about ways to screen your child for developmental delays at well-child visits.</p>	<p><u>Is it Autism?</u></p>  <p>It can take weeks or months to get an appointment with an autism specialist. Talk to your pediatrician about what you can do while you wait.</p>
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<p><u>In the Emergency Room it can be hard to:</u></p>  <ul style="list-style-type: none">• Explain your child's needs.• Wait a long time for care.• Some families may feel rushed.• Some families may feel judged by staff and other patients.	<p><u>Families can help Emergency Room Staff by:</u></p>  <ul style="list-style-type: none">• Showing hospital staff how to communicate with your child.• Telling staff about your child's autism symptoms.• Working with hospital staff - you are the expert on your child!
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<p><u>What can Doctors do to help?</u></p>  <ul style="list-style-type: none">• Keep wait times short!• Create a calm space.• Make parents a part of all medical care.• Communicate in the patient's preferred way (talking, typing, etc.)	<p><u>What can parents do to help?</u></p>  <ul style="list-style-type: none">• Ask staff to play a calming movie• Watch videos on a phone or tablet• Ask to wait in a quiet, calm space• Tell staff about your child's autism and how to help!
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Families can face many road blocks when they need medical care for their loved ones with autism. When a child is young, spotting the early signs of autism and getting a diagnosis lets the child get early-intervention therapy quickly. But many pediatricians feel they need more training on how to screen and treat their patients with autism³. Many families have to wait a long time for an appointment with a doctor who can diagnose children with autism¹. Children whose parents have less education, or who have mild autism symptoms and higher IQ scores, are often diagnosed at older ages⁶. Also, white and non-white children with autism don't get the same amount of care from specialist doctors (doctors who focus on just one area of the body like the stomach or the brain). This could be because some families had a hard time getting medical care, were not referred to specialist doctors, or the family did not follow-up with the specialist doctors⁷. Telemedicine – meeting with a health care provider over the internet - is one way to help. Telemedicine lets families meet with health care providers who might be too far away to visit in person. It also lets health care providers share information with each other including expert information about caring for children with autism^{3,4}.

Going to the emergency room can be very hard for people with autism and their families. Families can have a hard time explaining about autism and what their child needs. They may have to wait a long time

for care. Or they might feel rushed by staff who are not used to caring for patients with autism. Families also may feel that the emergency room staff does not see them as experts on their child or teen with autism⁹. Some families find it stressful to tell the emergency room staff that their child has an autism diagnosis because they are afraid of being judged. Health care providers agree that explaining that the patient has autism is an important part of being able to give the patient the best care⁸. One tool that can help families in hospital or emergency room situations is an Autism Specific Care Plan. Families can create their own Autism Specific Care Plan and bring it with them to share with hospital staff. An Autism Specific Care Plan helps families give hospital staff information on how to best communicate and interact with their child and keep them safe. Families who use Autism Specific Care Plans feel happier with their care and feel that health care providers are better at working with their child or teen with autism². Hospitals and emergency rooms can also think about making changes to help patients with autism. Small changes such as keeping wait times short, creating a calm space, and playing a movie, can all help lower anxiety for kids and adults with autism. Making sure parents are part of all medical care and treated as experts on their child can help both families and staff. Finally, hospital staff can try communicating in the way the patient prefers (talking vs. typing, etc.)^{2,5,9,10}.

**Disclaimer: This summary is based on research conducted by Autism Treatment Network (ATN) members. It is not a summary of the entire body of research literature available on this subject*

Frequently Asked Questions

1. WHY IS IT HARD TO GET SERVICES?

- Many pediatricians need more training on screening and treating patients with autism³
- Families often have to wait months or even years for an appointment with a doctor who can diagnose children with autism¹

2. WHO DOES THIS HURT THE MOST?

Families who have the most trouble getting services tend to:

- Have less education
- Have children with milder autism symptoms and higher IQ scores⁶
- Not get the same amount of care from specialist doctors⁷

3. WHAT CAN HEALTH CARE PROVIDERS DO TO HELP?

- Pediatricians can access online training from autism experts to help them improve care for their patients with autism^{3,4}
- Pediatricians can stay in contact with families of children with autism to make sure the family is able to follow-up with specialist doctors⁷

4. WHAT ABOUT EMERGENCY ROOM CARE?

Families of people with autism often struggle with:

- Explaining their child's needs
- Waiting a long time for care
- Feeling rushed by staff who are not used to caring for patients with autism
- Feeling judged by emergency room staff^{8,9}

5. WHAT CAN PARENTS DO TO HELP?

Families can think about creating an Autism Specific Care Plan which helps:

- Give hospital staff information on how to best communicate and interact with the autistic patient
- Families feel happier with their care
- Families work as experts on their child together with hospital staff²

6. WHAT CAN HOSPITALS DO TO HELP?

- Keep wait times short for patients with autism
- Create a calm space
- Consider playing a calming movie if a patient is anxious
- Make sure parents are a part of all medical care
- Treat parents as experts on their child with autism
- Communicate with the patient in the way the patient prefers (talking vs. typing)^{2,5,9,10}

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