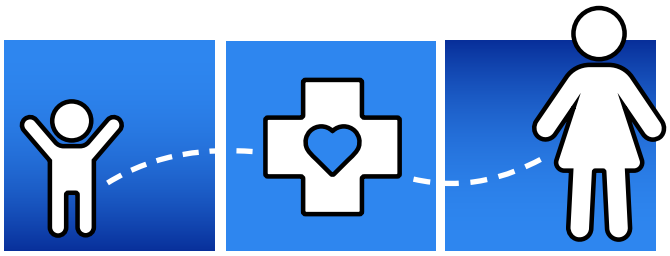

autism speaks®

Healthcare Transition Roadmap

A guide for navigating the switch from pediatric to adult medical care

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Introduction

A well-planned transition from pediatric to adult care is known to lead to **better medical care and an improved quality of life** for autistic individuals. The need for such a transition is made more important for adolescents with autism spectrum disorder (ASD) considering, compared to their peers without ASD, they are:

- 90% more likely to have additional mental health or co-occurring conditions.
- More likely to receive mental health services (41.8% vs. 22.1%).
- Three times more likely to have an unmet healthcare service need (11.0% vs. 3.2%).

Yet, the Centers for Disease Control and Prevention (CDC) reports that only one in 13 adolescents with autism spectrum disorder receive the recommended planning guidance to make the switch.

One barrier to successful transition is lack of provider training. **The Autism Care Network** (ACNet), made up of **20 academic institutions and children's hospitals** across the United States and Canada, is working with providers to develop guidelines and best practices to address this and accelerate autism care.

The other barrier is hesitancy on the part of autistic people and their caregivers. Why leave the comfort of a pediatrician who they may have seen since birth? By nature of an autism diagnosis, change is not easy. Add to that a looming deadline of adulthood and the multitude of other transition needs – education, employment and housing – and it is understandable that healthcare transition is at the bottom of the 'to do' list.

That is where this guide comes in, to break down the process into manageable parts for autistic people and their caregivers. Included is a timeline, a readiness quiz, tips for finding an adult provider, what to expect during the transition and how to advocate for the best possible care – supported by the expertise of autistic adults and medical professionals who treat them. With this, our hope is you can take better charge of and navigate this transition.

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Planning for Adult Medical Care

Why do adults have to leave the pediatrician?

Many wonder why they have to leave their pediatrician – someone they are familiar with and may have taken care of them almost all their life. The simple answer is: human needs change as we age, and medical professionals specialize to follow the lifespan.

Specifically, pediatricians are primary care specialists trained to identify and treat developmental, behavioral and physical conditions in infants, children, adolescents and young adults. After four years of medical school, they spend three years studying pediatrics as medical residents because children's bodies function much differently than adult bodies and go through many stages of growth and maturity.

Take a newborn. They are seen by a hospital pediatrician before they are discharged and then released with instructions to see a pediatrician for their first well-visit 2-3 days after they leave. The American Academy of Pediatrics then recommends that they are seen six times by their doctor before their first birthday. It is the start of an amazing, rapid period of growth and development that lasts through puberty and helps determine a person's health for the rest of their life. It is good thing that pediatricians focus on this time of life.

Not all pediatricians have the same age limit but many stop seeing patients over the age of 18 to remain focused on their specialty.

The exception is if your family sees a family medicine specialist, a primary care doctor who focuses on general health care for people of all ages, from newborn to seniors. In that case, there is no need to transition to a new medical provider into adulthood.

But if you or your child are among the majority who see a pediatrician, it is important to switch to a primary care physician (**PCP**) who cares for adults. Among them are internists, who only treat adults, and the above-mentioned family physicians. Sometimes both of these are referred to as general practitioners. For the purpose of this guide, we will refer to the collective group of primary care physicians who see adults as PCPs.

PCPs treat acute issues, or those that come on suddenly like coughs and fevers, as well as help to prevent and monitor chronic illnesses like high blood pressure and diabetes. They often focus on preventative healthcare, including screenings, vaccinations, and lifestyle. They are also able to make referrals to specialists and connect patients to other healthcare services, such as physical therapy or mental health services. Many PCPs utilize physician assistants, nurse practitioners and/or clinical nurse specialists in their practice settings who can help guide care.

PCPs are generally set up to interact directly with the patient rather than going through a parent like with the pediatrician. Their offices look different too — typically there are no primary colors, nurses or assistants in character-themed scrubs or rewards offered at every visit.

Timeline for transition: Breakdown by age

Switching to adult care does not happen with the flick of a switch at age 18, 21 or when a child is no longer covered by a parent's health insurance. Instead, it is a process, and doctors agree parents/caregivers should start planning for the transition between ages of 12-14.

Note: The Individuals with Disabilities Education Act (IDEA) requires schools to provide transition planning services for students with disabilities before the student turns 16. That planning must include strategies to build independent living skills. Making healthcare decisions and coordinating care is deemed an essential independent living skill. Therefore, preparing students with disabilities to take on these roles during adulthood should be a component of any student's transition plan. Autism Speaks **Transition Tool Kit** can further help you or your autistic teen/young adult chart a full path to transition.

The following is a general timeline, adapted from various ACNet sites

Under Age 12

Obtain copies of:

- Social security card.
- Passport.
- Birth certificate.

Start a medical record file with the above and:

- Medical history.
- Diagnostic materials.
- Medicine list (including current and past prescription medications).
- Developmental or educational testing results.
- Vaccination history.

Start establishing comfort in the medical settings by noting for your child all the things that make a pediatrician a pediatrician and how they look different from your own doctor.

Age 12-13

- Request an updated psychological assessment.
- Have a conversation with your pre-teen/teen to teach them about their health. They should know their diagnosis, what it means for them, any co-occurring conditions they have, any medications they take and why, and any allergies they have.
- Talk to your pre-teen/teen about adult medical care and the need to plan for it.
- Start to research adult primary care providers; look for autism experience and expertise.

Age 14

- Discuss sexual development, sexuality and healthy relationships.
- For girls and those with female anatomy, consider scheduling the first gynecological visit. Most will not need a pelvic exam. We focus on **Obstetrics and Gynecology** and what to expect and when in the Finding a Specialist section.
- Assess your child's readiness for healthcare transition using the federal program GotTransition's **Transition Readiness Assessment Questionnaire**.
- Encourage your child to ask the pediatrician questions about their health.

...continued

Timeline, *continued...*

- Encourage your child to start having time alone with their doctor during their visit, if safe. Start small and gradually increase it over time.
- Talk to the pediatrician about a plan for transitioning to an adult primary care physician. Share this timeline with them.

Age 15

- Consider what specialists you/your teen will need for co-occurring conditions and research them.
- Talk to your teen about what to do in case of a medical emergency. Again, make sure your teen can tell a first responder (EMT, ER nurse) what their diagnosis is, any medications they are on and any allergies they have.
- Identify supports needed during a doctor visit and start practicing them. For instance, if taking adult pill medication is a goal, versus liquid form, ask your pediatrician to try that out. **Note:** *These goals will look different for every teen.*

Age 16

- Discuss the referral to adult specialists with current pediatric specialists.
- Explore providers for additional areas including dental and vision care.
- Explore the idea of starting to have over-lapping annual appointments both with a primary care physician and the pediatrician.
- Assess your child's readiness for healthcare transition again using GotTransition's **Transition Readiness Assessment Questionnaire**.
- Practice or have your teen practice making a doctor's appointment.
- Review, modify and solidify the transition plan with the pediatrician.

Age 17

- Schedule appointments with all pediatric specialists to ensure transfer of care.
- Explore the idea of overlapping or joint appointments with both the adult and pediatric specialists.
- Ensure your child can identify their medical problems, medications and allergies without parent/caregiver support or at least know how to access that information.
- Teach your teen to carry contact information for medical needs in their wallet or cell phone. Or set up a **Medical ID on their smartphone**.
- Make a copy of your teen's medical record file and share it with them.

Age 18

- Have final appointments with pediatrician and pediatric specialists.
- Confirm adult providers have all relevant medical records.
- Confirm appointments with adult care specialists for any relevant co-occurring conditions.
- Review consent with your young adult. Independence and privacy are legal rights at age 18 unless caregivers have guardianship. The medical providers will now speak with the autistic young adult instead of the caregiver. The young adult can give the okay for caregivers to be at appointments and to have their medical information shared with caregivers.
- Consider scheduling a follow-up visit or phone call with providers to report how it went in order to prepare for a successful next appointment.

It is important to remember that every person is different. This timeline is a guideline and may vary for you. You or your autistic teen or young adult may have just started the healthcare transition process at 17, 18, even 20 years old. That's ok. You can still follow the steps. Additionally, rest assured all pediatric doctors are familiar with and sensitive to the transition process. There is grace and wiggle room in the timeline. It could take many years, which could provide a more comfortable transition, and could be staggered among doctors if multiple specialists are involved.

How to get started

It is one thing to have a timeline to transition in front of you. But it is another thing to be ready to make the switch.

How do you know if you are? As mentioned in the timeline, GotTransition, a program of **The National Alliance to Advance Adolescent Health** to improve the transition to adult medical care, can help you figure that out. It has both a quiz for **youth and young adults** and one for **parents/caregivers** that will help measure your readiness and offers helpful next steps for you depending on how you answer it.

Finding a Primary Care Physician (PCP)

How to find a PCP

One of the best sources for finding an adult medical provider is your pediatrician. If they have someone they recommend, ask them to make a call to the new doctor's office on your behalf or write you a referral script. Caregivers should also check with their own PCP to see if they will accept their autistic teen/young adult or if they can make a recommendation.

If you are near any of the **20 academic institutions and children's hospitals** in the ACNet, you can check with them or their website for recommendations. Or you use **Autism Speaks Resource Guide** to search for 'Primary Care' local to you.

Alternatively, you can check with your health insurance provider. Many have a searchable list of doctors covered by their plans on their website.

Questions to ask a perspective PCP

Once you find a perspective PCP, it is a good idea to call their office and ask the following:

- Do they treat any autistic patients?
- Are they willing to see a new autistic patient?
- What autism training do they have?
- What autism training does their staff have?
- Do they have a transition process? If so, what is it?
- Do they honor parallel care during transition phase and how do they coordinate sharing of information?

Think about the answers and if you are comfortable with them, schedule an appointment for an introductory visit.

What to do if the PCP has little experience with autistic people

Our collective knowledge of autism has outpaced the training the medical profession receives in caring for autistic patients. The ACNet is trying to close this gap. One site, Vanderbilt Kennedy Center, in Nashville, TN, has taken the lead in developing the kind of guidelines you seek. **Health Care for Adults with Developmental Disabilities** is an online tool kit they produced for primary-care physicians. Importantly, it contains a healthcare **Checklist for Autism**. This checklist can guide a physician through autism-specific considerations and recommendations for medical issues including sleep, dental health; gastrointestinal health, sexuality, mental health and much more.

The "considerations" section of the checklist highlights physical and mental health conditions that frequently co-occur with autism. The "recommendations" section lists useful exams and tests with their suggested frequency.

When it's time to transition out of pediatric care, we suggest that you bring this checklist to your or your child's new PCP. We also suggest if your new doctors have little experience with autism, you might likewise share the tool kit section on **Communicating Effectively** with patients who have developmental disabilities.

Many of the guidelines in the toolkit are based on best-practices developed by clinicians in the ACNet with the work made possible by the ACNet's role in the formerly federally funded Autism Intervention Research Network on Physical Health (AIR-P) which was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS).

The journal Pediatrics previously published a number of ACNet's best-practices research reports in a special supplement. You can access the **entire supplement** or direct your PCP to it.

PROVIDER PERSPECTIVE:
Tips for managing the switch to a primary care physician

**By Matthew O'Brien, PhD, BCBA-D, Clinical Psychologist,
University of Iowa Hospitals & Clinics, Center for Disabilities and Development**

Switching from the pediatrician to a primary care physician can seem like a big challenge for an autistic young adult and/or their caregiver. But starting with finding the right provider to managing the first visit, here are some helpful things to think about:

- Whether you have a referral from the pediatrician or found a PCP through your health insurance, it is a good idea to reach out to perspective doctors and make sure they are open to working with an autistic patient. Even if they don't have experience with autistic people, if they say they are open to it, that is a good sign. It is an opportunity for you to learn together and for you to teach them more about autism.
- It is good to schedule an appointment just to meet the new PCP. This initial appointment could be longer than a regular medical visit. It should be more a meet-and-greet.
- One valuable thing is for an autistic young adult and/or their caregiver to develop an introduction tool kit. All too often providers do not spend enough time with patients and the patient feels they are with someone who doesn't know them well. This addresses that. I emphasize full disclosure here. This should state who you/they are, some accommodations that have helped with visits in the past and some challenges. It is also important to share what you want them to know beyond the medical basics. Include social and mental health. It should include sensory issues and aversions. But keep it digestible for the provider.
- Ask for visuals and picture sequences for procedures and even of the office location. This works well with all patients with anxiety.
- A big issue in medical care with autistic people is disability etiquette. I don't think it's a bad thing for an autistic young adult or for a parent to also be an educator. You are the expert on your or your child's diagnosis. It is ok to share or ask questions about your experience and information you have gathered. It is ok for the provider to learn from you. It is also ok for them to research the information you provide further, as that is how they were trained.
- If you experience a provider who is condescending or treats the autistic young adult as a child, it is ok to find a new provider who does not engage in such barriers. When you don't have other options, it is a good idea to be honest and say why you're uncomfortable. As a provider if an autistic patient or their family told me they were uncomfortable and I could rectify the situation, I would. I think most providers want to do good work. We want to do better and learn.
- Re-establishing a relationship with a new provider can take time. No one is comfortable the first time. So plan to make it as rewarding as possible. Go with someone or with something special or plan to do something special after the appointment.

The First Visit with a New Primary Care Provider

What to Expect

For many autistic people, knowing what to expect is one of the best ways to reduce stress and anxiety about new situations and experiences.

One suggestion to make a first appointment feel less overwhelming is to schedule an office tour. Arrange to meet the staff, be shown around the office and ask any questions. As part of that visit or on a separate occasion you could schedule a meet-and-greet appointment with the doctor. This will allow time to ask questions with the reassurance that no physical exam or treatment will be involved. It also creates an opportunity to discuss any accommodations that would help make the visit better for you or your teen/young adult.

If the first visit does turn out to be for a physical exam, injury or illness, the process itself will be like a visit to the pediatrician. It will involve waiting in the waiting room, then being called back to have some basic measurements including vital signs taken. Those could include some or all of the following:

- Weight taken by having you stand on a scale;
- Height taken be standing with your back up against a wall;
- Body temperature taken most likely with a digital thermometer either orally, through the ear or even with a wand swiped across your forehead;
- Heart rate measured by taking your pulse, typically with the medical assistant placing two fingers on your wrist where they can feel your pulse and counting the number of beats;
- Oxygen level measured with a pulse oximeter, a noninvasive, pain-free, digital device placed on the index finger for a minute;
- Blood pressure measured with an arm cuff that is inflated like a balloon and becomes tight for a second before it deflates. The doctor or medical assistant listens for pumping sounds as notes when they are heard on a gauge attached to the cuff. You can watch a video of what an autistic patient can expect with a **blood pressure test**, courtesy of The Ohio State University Center for Autism Services and Transition (CAST).

If necessary, the PCP may have you undergo some procedures during your visit. You can watch more videos courtesy of CAST of the more common ones below:

- **Blood draw**
- **Electrocardiogram**
- **Vaccine or injection**

You will most likely be asked to change into a gown for the physical part of your exam. If you are not told, ask whether it should be open in the front or back, if you can keep undergarments on and where you can put your clothes. If you have sensory issues with a gown, you should make the doctor and their staff aware of this when you make the appointment or during your tour or meet-and-greet visit and come up with a plan to handle this.

The doctor will then come in, review your medical history, ask you questions about your current health, ask about issues or concerns and then do a physical. This will involve touching and the use of instruments on the body, including a stethoscope to listen to the heart. If you or your child has had issues in the past with any part of a physical, the doctor and staff should be made aware ahead of time so a plan can be made to handle this.

During transition planning, it is common for parents/caregivers to begin stepping out of the exam room for part of the visit when a child reaches adolescence. So some young adults may already be used to speaking to their doctor one-on-one. However, it is always up to the individual whether they have someone present for all, some, or none of the visit. The doctor should accept whatever the preference is, though if a parent or support person is present, the doctor should direct their communication to the individual and allow them to communicate their own needs as much as possible.

It is important to note that once an autistic person turns 18, doctors talk to them, not parents/caregivers. We will cover 'Turning 18' more in the Considerations section. Confidentiality between patient and doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA. This law does give privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state's minor consent laws for more information.

What to Bring

Before arriving at your first appointment, it is a good idea to make sure all your medical records are transferred to your new PCP. You should contact your pediatrician's office about having records sent to the adult PCP. Sometimes time prohibits this. Regardless it is a good idea to bring your medical record file, just in case. It can reduce stress at the appointment and make it run more smoothly. Your new doctor may require you to fill out forms. Ask about this when you make your appointment. If there will be forms, ask if you can get them in advance or find them online or in a patient portal, which doctor offices and large healthcare systems are increasingly using. Be prepared that these forms may ask for duplicate information. Be patient with them.

You will likely be asked to provide an insurance card and a driver's license or photo ID at every medical appointment. Parents or support people may also need to provide a driver's license or photo ID to enter the facility.

Many autistic people find that verbal communication can be challenging in stressful situations such as medical appointments, so they find it helpful to write or type out their concerns in advance. Some individuals may need support to do this. Even if the individual is not ready to communicate with the doctor one-on-one, doing so with a parent or support person who can take notes is a good step in self-advocacy.

In addition to the necessary documentation and paperwork, consider other items that could make the experience more comfortable. For someone with sensory issues, think about bringing sunglasses or headphones. Make sure phones or other tech devices are charged, and if possible, bring headphones to avoid disturbing other patients.

If you have trouble with waiting rooms, call ahead and find out if your provider is running on time. If there is going to be a delay, ask how long. Ask if it is ok if you delay your arrival then, or if you can check-in on time and then go wait somewhere more comfortable until you can be seen.

Finding An Adult Care Specialist

Primary care providers are trained to diagnose and treat many common illnesses and some chronic conditions, like asthma and high blood pressure. But if the condition is rare, complex, and/or the PCP thinks you need focused care, they will refer you to a specialist. Common ones are cardiologists for heart health, dermatologists for hormones and metabolism issues like diabetes and thyroid problems, and gastroenterologists for the digestive organs, including the stomach, bowels, pancreas, liver, and gallbladder. There are also specialists who focus on diseases, like cancer.

Sometimes a medical issue is covered by overlapping specialists and your PCP. Whether you have such an issue or if you just have multiple specialists, coordinating care is important so that each one knows about any other conditions you have and the treatments you're receiving. You may need to give your permission for different doctors to share information about your health with each other.

How to find a specialist

If you need to find or see a new specialist, just like finding a PCP, you can start by asking your existing pediatrician and pediatric specialists. The ACNet, **Autism Speaks Resource Guide** and your health insurance provider are also good sources to check. If you need to find a specialist for a rare condition, online condition-specific organizations and their patient groups are another great source.

Challenges to finding specialists

It can be more challenging to find a specialist who also has experience with autistic adults than it is to find a PCP. This is because there are fewer doctors in each specialty than there are in primary care, and their training is more focused on a particular body system. Depending on where you live and what kind of specialist you need, your options may be limited. As Dr. O'Brien mentioned with finding a PCP, call and ask any perspective provider if they are open to treating autistic patients. *"Even if they don't have experience with autistic people, if they say they are open to it, that is a good sign. It is an opportunity for you to learn together and for you to teach them more about autism."*

Specialty Focus: Obstetrics and Gynecology (Ob/Gyn)

The American College of Obstetrics and Gynecology (ACOG) recommends a first visit to the gynecologist for girls ages 13-15 and a wellness checkup each year. Their article, **Should My Teen See an Ob/Gyn? Here's What I Tell Parents** is a good explanation as to why.

How to find an Ob/Gyn

Several kinds of providers can do a well-woman checkup, including:

- A gynecologist.
- A family practice doctor.
- A family nurse practitioner.
- A women's health nurse practitioner.

To find a provider who specializes in caring for young girls and women with autism:

- Ask your daughter's pediatrician or primary care provider to recommend a provider.
- Ask your friends and other autism families in your community.
- Use this **listing of gynecologists** from the Autistic Women & Nonbinary Network to find a provider in your state.
- Look for an **Autism Care Network** site in your area.

What to expect at the first visit and prior to age 21

Rest assured, **the first visit to the gynecologist as a teen or young adult will most likely just include a talk between patient and provider about development and a brief physical exam**. Unless you or your child present with abnormal bleeding or pain, a pelvic exam will not be done. If you are sexually active, you may have tests for certain sexually transmitted infections (STIs). Most of the tests that teens need can be done by the doctor with a urine sample.

The first pelvic exam, which is an exam of the pelvic organs, and pap smear, a procedure to test for cervical cancer, are typically done at age 21. During the appointments leading up to this, the gynecologist can explain a woman's anatomy, explain and show images of the procedures and share the instruments that are used. Women with autism are less likely than other women to go for annual well-woman visits. So getting used to or having your autistic young adult get used to going for these checkups is a good way to promote healthy living throughout life.

Included in a gynecological exam will be a breast exam and a discussion about doing a self-exam to check for signs and symptoms of breast cancer. Forty percent of diagnosed breast cancers are detected by women who feel a lump, so establishing a regular breast self-exam is very important. The National Breast Cancer Foundation has both a **video and guide** to help teach about breast self-exams.

The 'Ob' part of Ob/Gyn refers to obstetrics, the specialty concerned with childbirth and the care of women giving birth. Having trained in both, most physicians will practice both. But some will focus on one field over the other. If and when the time is right to think about having children, you want to make sure you see a doctor who practices obstetrics. Midwives, healthcare providers who are trained to provide obstetric and gynecological services, can also be consulted.

Hospitalization

A hospital stay can be stressful whether planned for a procedure or an emergency. But both are easier to handle with some planning.

Before you ever need to go to the hospital

1. Be aware of the different hospitals in your area. A few things to find out about each:
    - Which ones are in network with your insurance?
    - Does your primary care provider and/or specialists have admitting privileges?
    - Does the hospital have programs for adults with disabilities?

This information will help you decide where to go first should you ever be in an accident or suddenly become sick and need to go to the emergency room.

2. Prepare an emergency bag or two. It should be waterproof and kept by your front door and/or in your vehicle. Among the things on this **downloadable checklist** of what it should include provided by the Adult Autism Health Resources of Harvard Medical School are:
    - Copies of medical insurance information
    - Earplugs, earbuds or headphones to block out noise
    - Reading and writing material (to take notes)
    - Change of socks and underwear

3. Finally, you should make sure you let your family members, emergency contacts and primary care providers know you have a preferred hospital and an emergency bag.
    - Talk to your PCP and make a plan for emergencies and hospital stays. For example, you can ask if your PCP would be willing to speak to your treating doctor should you be in the hospital or ER. By requesting that the treating doctor call your PCP, you can ensure your needs are being clearly communicated, doctor-to-doctor, by someone who knows you personally.
    - Make sure your medical records include a contact person or people permitted to receive medical information.
    - Keep an up-to-date document with a list of medical conditions, medications, allergies, and names and contact information of your PCP and specialists.

What to consider when staying in the hospital

- Ask if you can be placed in a private room as an accommodation.
- In most situations, patients can bring someone along for appointments, tests, procedures, hospital visits and treatments. You might need someone to help you communicate or take notes for you, complete daily living tasks or navigate the process. If a staff person denies access to your support person, tell them that you have a disability and need an assistant. Most places have policies to allow this even when a visitor is not normally allowed.
- Most healthcare centers and hospitals have a social worker on duty or a "patient ombudsman" whose job is to help you advocate. A social worker or ombudsman can help you understand your rights, make a complaint if necessary and get the help you deserve.
- Doctors often work in groups or teams based on their specialty and take turns seeing patients in their rooms each day. This means there will be a lot of people coming and going from your room, and many of them will be unfamiliar to you. It can be hard to keep both people and information straight, especially when you've been fast asleep or aren't feeling well. Don't be afraid to ask providers to identify themselves and to clarify if you don't understand something. It can be very helpful to have a support person present when doctors do their daily rounds. It's also a good idea to take notes.
- When it comes to any disability-related needs or accommodations, be prepared to repeat yourself a lot. Think about how you can communicate your specific needs in this situation so that the doctor and staff can better support you as an individual.

SELF-ADVOCATE PERSPECTIVE: Having your needs met in a hospital

By Lydia Wayman

As an autistic person who has experience with specialists, hospital admissions, and trips to the emergency room as a child and an adult, I have seen the best and worst of the medical system. So, how does someone with a disability that affects their ability to communicate, process sensory input and handle change navigate a system that demands these very things when the stakes are at their highest?

Not easily. But there is a lot to be said for preparation and practice, and while not every autistic person who finds themselves in a hospital has the benefit of many years of experience, I hope that others can learn from some of mine.

Communication is key in any medical interaction. In many cases, this communication has to happen in a scenario that is the opposite of accommodating for many autistic people. Stress levels are typically high and sensory regulation is impossible. Routine is disrupted. Support people may or may not be present.

As much as possible, I try to deal with doctors who are familiar with me and how I communicate. I choose to see doctors who understand both my challenges and my strengths and don't see the involvement of a support person as a reason to treat me with less respect. Unfortunately, you can't pick your doctors in the hospital or emergency room, and I have been in situations where my safety was put at risk because of communication issues and how doctors viewed me.

During a period of time when I was frequently in and out of the emergency room and often being admitted, I realized that simply having autism listed as a diagnosis in my records didn't give the doctors much useful information. I created a half-page document that explained how autism affected me in the context of the few minutes they would spend interacting with me. It included information that would help them help me, like the fact that I need extra time to respond to questions, that communication is difficult or impossible when I'm overstimulated (including when someone is touching me), and that my mom may sometimes help by "translating" but not by speaking for me.

This document was a good start. I printed out multiple copies and brought them to the emergency room or hospital with me. However, due to the number of providers involved in my care and a tendency for them to glance at the paper and then leave it behind, I could never be sure who had seen it. I still felt a lot of anxiety each time I had to go back to the hospital. Since that was a constant risk for several years, this anxiety was affecting my daily life.

I saw an article about an emergency room physician who worked at the hospital I went to and had recently been appointed to a leadership position in research. It mentioned his work studying the experiences of autistic children seeking emergency medical care. Since the hospital had no real support in place for autistic patients, my mom suggested we try to get in touch with him about ways of making these visits less overwhelming and safer.

When my mom sent an email on a Friday afternoon, she did not expect him to call back that evening. This doctor first asked to see the document I had created and then asked if it was okay if he discussed it with the medical director of the ER and the director of nursing. They were able to put notes in my electronic medical record. Included among them: Rather than having a team of doctors enter my room, one person should come in at a time. When possible, the lab and x-ray technicians should come to me in my room. It also notes that the hospital gown is a major sensory aversion for me.

While I have not been to the hospital in several years, the reality is that there will almost certainly be medical emergencies in my future. Knowing this information exists in my medical record history for anyone treating me to access eases the burden of making my needs known. This allows me to focus on what really matters — getting the medical attention I need. The reassurance that I have a safe place to go, if and when I need it, gives me peace of mind.

Additional Considerations in Transition Planning

Rights, Accommodations & Self-advocacy

The Americans with Disabilities Act (ADA) is a federal law that requires equal access to healthcare for people with disabilities, including people with autism. It says you have the right to receive medical treatment free of discrimination; you or your child cannot be denied medical care because of your or their disability. Knowing this right is the first step in promoting self-advocacy among autistic teens and young adults.

Making healthcare accessible is typically done by providing "reasonable accommodations". An accommodation is a modification that allows you or your child to participate in their healthcare the way a person without a disability can. Accommodations are not defined in the ADA. "Reasonable" is also not defined in the ADA though the law says modifications must be "feasible" and "plausible" and cause "undue hardship." The law is purposely broad since it is expected that accommodations will be handled on a person-by-person basis and could change depending on the setting and situation.

The following are examples of possible reasonable accommodations that can happen in healthcare:

- Sensory-friendly waiting areas
- Help with paperwork that needs to be completed, or an advance copy of it
- A schedule of the visit outlining what it will entail.
- Extra time for communication during all aspects of the appointment.
- Using a patient portal or an app to schedule appointments, get appointment reminders or request medication refills.
- If you do not use speech, a communication method that works for you. (Example: AAC device or American Sign Language (ASL)).
- Allowing a support person in the exam with you.
- Note takers or real-time transcription services.

If you need accommodations, talk to your doctor and/or their office staff, ideally before you have a visit. Learning how to communicate to have your or your child's needs heard is another, lifelong self-advocacy skill. The following are a few tips that may make your request for accommodations more effective:

- Approach the doctor and/or their staff with a request to discuss accommodations.
- Explain the way(s) that your disability makes it difficult to get good healthcare. Give concrete examples.
- Give some ideas of possible accommodations. Ask if they would be possible and if the doctor or staff have other ideas that could work in their office or practice.

Additionally, you could create an *Autism Healthcare Accommodations Report* developed by the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), funded by the National Institute of Mental Health, which outlines your needs and recommended accommodations. The report is custom-generated after you answer some questions using their digital Autism Healthcare Accommodations Tool (AHAT). Access to that tool and a **sample** of the report, including an accompanying letter to give to your provider, are **here**. If you create this, is recommended you schedule a pre-appointment visit with your provider just to review this report.

Self-advocacy tips for LGBTQIA+ autistic adults seeking medical care

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A study published in the February 2020 from the *Journal of Autism and Developmental Disorders* revealed a wide range of health disparities among LGBTQ+ autistic adults, including high rates of mental health conditions, unmet needs for mental and physical healthcare services and even medical providers denying them services, compared to straight, cisgender autistic adults. With that in mind here are tips for LGBTQ+ autistic adults when seeking medical care:

- Before going to an appointment or procedure, write down or print out your concerns. If it gets too hard to talk, you can hand your questions and concerns to a provider.
- Providers should use your preferred name and pronouns. If they won't or if they tell you they can't, talk to someone in charge. Sticking up for yourself can be hard, but you have a right to be called by the name of your choice and to have people use the pronouns you want them to use.
- No one can deny you gender-related health care just because you are autistic, are intellectually disabled or have a mental health condition. You still must comply with the same procedures as everyone else, but you cannot be refused outright. Speak up if this happens to you.
- Several of these tips suggest talking to someone in charge. That can be difficult or anxiety-provoking. Most healthcare centers and hospitals have a social worker on duty or a "patient ombudsman" whose job is to help you advocate. A social worker or ombudsman can help you figure out your rights, complain if necessary and get the help you deserve.
- It would be nice if all healthcare providers were trained in autism and in LGBTQ+ issues. Unfortunately, this is not the case. While it isn't necessarily fair, you may have to explain what your autism means to you or what you need as an LGBTQ+ person. Thinking in advance about how you might explain what you need, what you can or cannot do and what strategies work for you can reduce the stress when you encounter a provider who does not understand yet. And you will likely make a difference for those coming after you.
- Lastly, you have the right to say no. Healthcare providers give us information and choices. Ultimately, your health treatments are your decision. If you ever feel pressured or uncomfortable about a health care decision, talk to someone you trust right away to get support.

Turning 18

After a person turns 18, informed consent, the right to make decisions about your own life, shifts into their hands — even if they may have developmental or mental impairments that make them incapable of making important life decisions.

After age 18, parents can no longer:

- Make medical decisions for their child.
- Decide where or how their child should live.
- Sign documents on behalf of the child.
- Receive medical updates from doctors without written permission from the child.

Specifically, the PCP and specialist talk to the adult patient, not the parents and caregivers. Health information and medical records are private and can't be shared without the adult patient's consent.

For autistic adults aged 18 and older: Making your own healthcare decisions

It is your right to make your own healthcare decisions. Participating in your healthcare transition planning is the first step to helping you make informed ones. That includes learning as much as you can about your medical history – your diagnosis, any co-occurring conditions, any medications you take and any allergies you have – and discussing these with your parent/caregivers and your medical team. Ask questions and ask for more information or who or where you can learn more. In the next section, For parents/caregivers of autistic adults turning 18, read how they can obtain legal permission to continue to make decisions for or with you.

The Arc, a national community-based organization, advocates that people with intellectual and developmental disabilities must make many daily and major life decisions, just like people without disabilities, including talking to a health care provider about medical care. They have developed a guide, **Making My Own Healthcare Decisions For People with Disabilities**, can help you make, review and adjust a healthcare decision-making plan to share with your doctors and loved ones.

For parents/caregivers of autistic adults turning 18

Parents of children with disabilities will need legal permission to continue making decisions for them after age 18, even if the child is financially dependent on parents and/or resides in an assisted facility. State laws require the needs and wants of a disabled adult be considered as much as possible for every decision made about that individual's living conditions and medical care.

If you feel that at 18, your child is not or will not be able to make important legal decisions on his or her own behalf, you may want to consider pursuing guardianship so that you can retain your ability to make such decisions for him or her.

Ultimately, an Order of guardianship or conservatorship terminates or severely limits the ward's rights and freedoms. State laws require that less restrictive alternatives are explored before guardianship or conservatorship is ordered. Some alternatives include Power of Attorney - a grant of shared authority by one person (the principal) to another (the agent or attorney-in-fact) to make decisions regarding finances or health care – and Representative or Protective Payee – a person appointed to manage benefits like Social Security.

You can learn more about guardianship, conservatorship and power of attorney plus the financial implications in the following:

Autism Speaks Transition Tool Kit

Autism Speaks Financial Planning Tool Kit

Family ECHO: Autism, a virtual training series developed with Nationwide Children's Hospital of the ACNet. The episode "**The Second Act**" includes a discussion on healthcare, including legal considerations with guardianship and power of attorney, and co-producing care with your medical team. Find and register for upcoming sessions **here**.

Changes to SSI Eligibility

If you or your child received SSI benefits before turning 18, the standards under which they receive those benefits change Before 18, the Social Security Administration (SSA) attributes part of both parents' (legal guardians') income to their child's resources to determine their child's eligibility. Upon the child's 18th birthday, the parents' income is no longer considered when determining the means-based eligibility limits.

This handout from the University of Massachusetts Medical School outlines if you can keep your SSI after 18, if you can work without having your SSI check amount reduced. If it is determined you are no longer medically eligible for benefits after the age 18-redetermination, your benefits may continue if you are participating in , if you are participating in an approved program of special education, vocational rehabilitation (VR), or similar services.

Some examples of appropriate programs include:

- An Individualized Education Program (IEP) for a youth who is between ages 18 and 21.
- A VR agency using an individualized plan for employment.
- Support services using an individualized written employment plan.
- A written service plan with a school under Section 504 of the Rehabilitation Act.
- An approved Plan to Achieve Self-Support (PASS).

For additional information, read **What you Need To Know About Your Supplemental Security Income (SSI) When You Turn 18**.

Additional Resources

Autism Speaks Financial Planning Tool Kit

Autism Speaks Roadmap to Self-Empowerment for Autistic Adults

Autism Speaks Transition Tool Kit

Center for Transition to Adult Health Care for Youth with Disabilities

GotTransition