

Health Care Transition

This informative publication ensued from the collaborative works of Family Network on Disabilities and ASAN. Family Network on Disabilities understands and respects the beliefs and opinions of those who choose not to use “Person First Language.”
At FND, we respectfully prefer to use “Person First Language.”

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An Introduction

Transitions can be difficult, and transitioning from children's healthcare to adult healthcare can be especially difficult for young autistic people. However, the transition can be made less challenging with preparation

One way to help the transition to be less challenging is to begin thinking about and discussing the responsibilities as early as possible with a parent or guardian.

- Do you know how to find a physician?
- Are there traits you are looking for in a physician?
- Do you know how to make a medical appointment? (If needed, role-play for practice.)
- Do you have any other conditions your new physician should know about?
- Are you taking any medication(s)? What type, and for what reason?
- Do you keep track of current medications (types, doses, times)?
- Have you filled your own prescriptions?
- Can you describe to a doctor your symptoms (stomachache, headache, earache, etc.)?
- Do you understand your insurance coverage/policy?

Knowing the answers to these important questions before making the health care transition will be a great start to making sure that your needs are met. Taking full responsibility for your needs is empowering, and an important part of being a self-advocate.

What is it?

A transition is a shift or movement from one thing to another. In this tipsheet, "transition" means moving into adulthood. This includes the changes in responsibilities, expectations, and abilities that come with that.

Transitions can be difficult for anyone; most people take comfort in familiar settings. People with ASD often use routines in order to better navigate life, and a sudden change - getting a job, or changing health care plans - can be very unpleasant. Preparing people with autism for change, and making the change less sudden, makes this easier.

Many changes in life are unavoidable. Fortunately, you can cope with these changes.

Goals

Health care choices can be very confusing for adults and young adults. There are many new choices of ways to get healthcare now. Figuring it all out isn't easy. Once you turn 18, the law says you are an adult. This means that you are responsible for making many of your own decisions. One of the decisions you will need to make is about choosing your health care coverage (health insurance when you go to a doctor).

Before you turn 18, your parents or other adult helpers make many of these decisions for you. Now they can go over information with you, explain it, help you figure out your own needs, and make suggestions. But the final decision is yours.

You can look through choices now. By January 2014, you will need to sign up for the plan you pick that is the best for you if you are 18 and not covered any more by another plan (like your parents' health care plan). Here are some places to read information to help you make the right choice for you. You can do this online.

<https://www.healthcare.gov/> is a website where you can choose the right health care plan for yourself. It is set up by the government to help you. It is also easy to use- you just click on the ideas that match your needs. Some answers are yes/no, others you just click a circle, then click the "next" button. You then select the idea that best fits you.

You can read a lot of information. It may help to have another adult read with you

to explain some words or help you figure out what your situation is. There are answers to many questions people have asked. You can also type a question to ask a person who will answer your question.

You can read about the different health care choices in your state, and compare each one. You can then choose the one that fits your needs and sign up for it. The price for each choice will be available when you sign up.

Self-advocacy and self-determination

"Self-advocacy" and "self-determination" mean people with disabilities having as much control as possible over their lives. In the autistic rights movement, self-advocacy calls for autistic people to be able to decide for themselves what their lives will be like, and how to live them.

While autistic people may need help from outside sources, we get to decide what that help may be and who we wish to get it from. Self-advocacy applies to health care because having control over which doctors you see, understanding the information they tell you, and deciding what to do or not do about your own health, is a part of having control over your own life.

Health Care Needs

When looking at the healthcare needs of those on the autism spectrum, consideration must be given to physical as well as mental conditions, since many autistic people may also have other diagnoses. In order to capture a complete picture of their healthcare needs, all conditions should be included in their diagnosis and treatment.

These conditions may include: anxiety, insomnia, bipolar disorder, sensory processing disorders, ADHD, OCD, gastrointestinal problems, such as IBS, Tourette syndrome, immune system disorders, phobias, seizures, allergies, motor coordination problems and depression.

Healthcare treatments should also take into account the fact that the majority of people with ASD have sensory issues that may keep them from seeking treatment in the first place. Some autistic people are sensitive to strong light and may not be able to handle sitting under a strong examination lamp. This is particularly the case in dental situations. Others may hate smells such as disinfectants or perfumes, and fragrance-free locations should be used. Auditory overload can occur in a normally noisy, hectic hospital treatment area. Since many autistic people have several sensory issues, getting them into a quiet, private exam room as soon as possible would help to lessen overload, which may keep the person calm and ease any anxiety they may be experiencing.

Health Care Transition

Growing up and learning to become an adult is difficult for all young people, but it can be especially challenging for autistic people, as they may have special health care needs in addition to the emotional and communication difficulties typically inherent with being autistic.

To best prepare the young adult for this transition, family members/caregivers need to start including the youth as early as possible with anything having to do with their healthcare needs, so that when they reach legal age, they will be familiar with the concepts and not surprised by an abrupt shift in responsibilities.

The following is a list (in no particular order) of some things that should be considered in this regard.

- When you take the youth to a doctor visit, be sure and include them in the discussions with the doctor; don't simply talk with the doctor as if the youth is not present.
- If the youth has sensory processing issues or difficulty following verbal instructions, be sure and request that the doctor provide written details. Go over this at home with them, getting feedback from the youth to ensure that they understand what has been discussed, what instructions s/he will have to follow, etc.
- If at all possible, allow the youth to choose between options on their treatment, as this actively involves and engages them in their own health care decision. For example, if they need to take a medication, and the prescription can be filled as either a pill/tablet or as a liquid, let the youth choose how they would prefer the medication.
- If the youth is like most young people, and very involved with computers, use that to your advantage when working to engage and involve them in their own medical treatment. Have them Google whatever medical issue they are facing, look up diagnoses, treatment options and anything else relevant to the issue. Discuss them with the youth, steering them towards the more viable options (as opposed to the less reputable websites). Knowledge is empowering, and giving them a hands-on way to explore their medical issues can be very positive.
- Should daily medication be required, work with the youth to take responsibility for their medication themselves. Come up with a way for them to monitor and take their medications on schedule. This could be via a visual chart with medications, days & times that are checked off when taken, a calendar reminder that pops up on their computer or smart phone at the appropriate times, or simply a MTWTFSS pill organizer as is used by many people that need to take medications regularly.
- If medication or treatments are required, be sure that the youth understands the reasons for them, and what the possible physical consequences are if

they are not followed. Don't simply give them ultimatums of "you have to take this because the doctor says so". That may be fine for a young child, but for a youth you're teaching to make adult decisions, more explanation and reasoning should be provided.

- Because many autistics have difficulty functioning in, and dealing with, emotionally-charged environments, try to keep your discussions at home and at the medical facility on a non-emotional, factual level as much as possible.
- Teach your youth the entire process of how to access medical treatment, including how to make a doctor's appointment, how to get a prescription filled, and how to keep track of the medications that they are taking. Again, if they are better dealing with written instructions, then do so. Write up a list of the doctors they see, along with notes on what each doctor does (i.e. their GP, allergist, cardiologist, therapist, etc.) Include their phone numbers and office hours. Then practice with them to see that they can look up their allergist's number, place the call, and make the appointment, with you there to encourage and assist if necessary. Do the same with detailing how to get a prescription filled.
- Be sure the youth understands how to describe their symptoms to a doctor. Practice this at home, with roleplaying if necessary. Teach them to be as

descriptive and detailed as possible, explaining that the doctor needs specifics on such things as locations of pain, the intensity of it, and in what instances it occurs. If they are not comfortable with doing this verbally, let them use their laptop or smartphone to convey the information.

While it may be difficult for parents or caregivers to hand over responsibility for their youth, it truly is in the autistic youth's best interest to learn how to navigate and make their own medical decisions. The sooner the process starts, the easier and less frightening it will be for everyone involved.

Healthcare Providers

If “pediatric” is in the title of your doctor, sometime between the ages of 18 and 21, you will have to switch to an adult doctor. Exactly when this happens is up to you and your doctor.

If you’ve always seen a family practitioner, you will not have to change. If you have a pediatrician as your primary care doctor, you will need to transfer to a family practitioner or internal medicine doctor (internist). Family practitioners (FP’s) see children, pregnant women, and adults. FP’s tend to be very good at preventive care. Internists specialize only in adults. Internists are comfortable handling patients who have more than one illness and complicated medical situations. If you’re seeing a specialist - such as a pediatric neurologist - for seizures, you will have to find an adult neurologist, who will probably be called just a “neurologist.”

Your primary care doctor can recommend a specialist or you can ask people you know to tell you about their experiences with doctors. Nurses are especially good people to ask.

Rights and Responsibilities

When it comes to your involvement with your health care, you have certain rights and responsibilities.

You have the right to have all the equipment at your health care provider’s office be accessible. For example, exam tables and weight scales should be physically reachable and useable by you, and the office should not be so loud or overwhelming as to prevent you from being there. In some cases you may have to ask that your access needs be met, but you have the right to have this request be honored. You also have the right to extra time on visits if you need that time, and to bring in your service animal.

You have the right to get the health care services you need, and not be discriminated against in getting those services.

Communicating with Providers

Communicating is a two-way street – giving and receiving information. If you are going to take care of yourself and stick up for yourself, you must be able to communicate in both directions.

A starting place for communicating with your health care provider is to take all your medications or a list of all your medications to every appointment.

If you have more than one or two simple things you want to discuss with your doctor, it helps to make a list. If you can be specific about what is bothering you, you will give your doctor the best possible chance of making the correct diagnosis and treatment decisions.

- What is bothering you? (sharp pain, crampy pain, nausea, etc.)
- How long have you been noticing the discomfort? (two hours, a day, a month)
- How long does the discomfort last? (seconds, hours, all the time)
- Does anything make you feel better or worse? (eating, lying down, exercising)
- How bad is the discomfort? Using the numbers 0 through 10, where 0 is feeling fine and 10 is the worst you've ever felt, can help your provider know how best to help you.

When the provider tells you what is wrong and what to do about it, ask any questions you have about what the diagnosis means and what you'll be expected to do about it. (How long will it be before I am feeling better? Can I take this medicine with food?)

Barriers

Young people on the autism spectrum may experience challenges or barriers when transitioning from pediatric health care to adult health care.

Barriers may consist of:

- you not feeling ready to transition.
- transition requiring careful planning and preparation.
- you having difficulty being engaged in the process.
- health care provider for adults not being trained to work with those on the autism spectrum
- health care providers unwilling to provide individual care or information to adults with ASD (which requires research, patience, and time)
- health care provider viewing work with ASD patients as unprofitable
- you or your family lacking understanding of your eligible covered services, changes or discontinuation of services, or medications under coverage, etc.



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Supports

One major support in finding healthcare is the Health Insurance Marketplace. Each state has its own marketplace where you can determine your eligibility for Medicaid or be matched to a variety of other insurance options.

<http://www.healthcare.gov>

You can find a directory of Centers for Independent Living in each state on this website: <http://www.virtualcil.net/cils/>

You can fill in this Health Passport form to easily communicate important information to health care professionals:

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_Spanish.pdf