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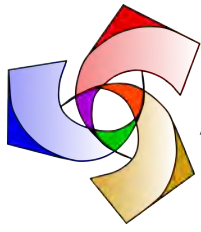
Healthcare Toolkit

Your Rights in Healthcare

Information and resources about disclosing an autism diagnosis, getting equal access to healthcare, understanding privacy and decision-making authority in healthcare.

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- Decision Making Authority



Your Rights in Healthcare: Disclosure

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Your Rights in Healthcare: Disclosure

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www.aaspire.org

Last Updated September 29, 2015

1 What is this topic about?

This topic is about the potential benefits or drawbacks of disclosing your autism spectrum disorder diagnosis to your doctor, your doctor's staff, or your health insurance provider.

2 Confidentiality - who can know about my ASD diagnosis?

In most cases, only people you choose can know about your ASD diagnosis. Your health information, including your ASD diagnosis, is confidential and protected under the Health Insurance Portability and Accountability Act, or HIPAA. That means your health information is kept secret by healthcare providers, healthcare staff, and insurance companies except in certain situations.

- If you choose to, you can give healthcare providers permission share your information with other people who you name.
- If you have a guardian or conservator, your healthcare providers can share your health information with them without your permission.

- In rare cases, your information can be shared legally with others without your permission (for example, if you are in danger of hurting yourself or someone else).
- In rare cases, your information can be gotten illegally (for example, by thieves or computer hackers).

Note that HIPAA privacy protection does not apply to most people outside of a medical setting. So if you tell someone like a classmate or co-worker, they do not have to keep your diagnosis secret, and they might tell other people.

3 Should I disclose my ASD diagnosis to my healthcare providers?

Whether to tell your provider about your ASD diagnosis is your choice. In most cases, the benefits of disclosing a diagnosis far outweigh the risks, but you need to weigh the risks and benefits for yourself to know what is right for you.

3.1 Possible Benefits of Disclosing an ASD Diagnosis

- **Understanding** - Knowing your diagnosis may help the healthcare provider to understand you better and to provide better healthcare.
- **Communication** - Knowing your diagnosis may help the healthcare provider not to misinterpret the things you say and do. This can help them to communicate with you better.
- **Avoiding Misdiagnosis** - Knowing your real diagnosis may help the healthcare provider not to misdiagnose you with something you don't have (for example, psychosis, anxiety, depression, malingering)
- **Accommodations** - If you disclose, you can ask for specific accommodations or strategies to help you get better access to quality healthcare. You

may also need a note from your healthcare provider to get accommodations in employment or other areas of your life.

- Referral for Formal ASD Diagnosis - If you don't already have a formal ASD diagnosis, your healthcare provider can possibly help you get one. More information can be found in the section on Adult ASD Diagnosis.

3.2 Possible Risks of Disclosing an ASD Diagnosis

- Misunderstanding - The healthcare provider may not know very much about autism and may misunderstand what it is (but you can educate them).
- Misjudging Abilities - The healthcare provider may underestimate your abilities (for example, think you don't understand things that you do) or overestimate your abilities (for example, think that because you can speak you can communicate well in speech). They might misjudge you based on their lack of understanding about autism (though, again you can educate them).
- Disbelief - Some providers may not believe your diagnosis if you do not fit their limited understanding of what people on the autism spectrum are like. Providers may also have negative opinions about people who self-diagnose autism.
- Confidentiality - While healthcare providers are not allowed to tell other people about your diagnosis in most circumstances (see the section on HIPAA), there is a very small chance of loss of confidentiality (chance that your diagnosis won't be kept secret).

4 Can I be denied employment if I disclose my ASD diagnosis to my healthcare provider?

Your healthcare provider is not allowed to disclose your protected health information, including your ASD diagnosis, to anyone outside of the healthcare system except in very special circumstances. Your healthcare provider is not allowed to tell your employer about your ASD diagnosis without your permission. See the information on HIPAA and Privacy for more information on who your provider is allowed to share your health information with. You do NOT have to tell your employer about your ASD diagnosis, or about any other medical diagnosis you may have. However, if you want to get accommodations in employment under the Americans with Disabilities Act (ADA), employers require you to disclose, and sometimes also require a note from your healthcare provider confirming your diagnosis. In that case, you might ask your healthcare provider to talk to your employer about your ASD diagnosis. The ADA protects people with disabilities from discrimination in the workplace. It is supposed to give people with disabilities an equal opportunity at employment. However, there is an exception within the ADA for employees who pose what is called a "direct threat." This means that the you may not be hired, or can be fired, if your mental or physical health would make the job unsafe for you or for co-workers. Who decides what is a "direct threat" is left vague. Whether or not a direct threat exists is determined on a case by case basis, so it depends on the particular job and the particular applicant or employee. Because of this, it is difficult to say how disclosing your ASD diagnosis to your employer would affect current or potential employment. If this is a concern of yours, seek legal advice in your area.

5 Can I be denied or lose my health insurance if I disclose my ASD diagnosis?

While it was once possible that you could be denied or lose your coverage because of an ASD diagnosis, it is no longer the case.

ASD is considered a pre-existing condition. A pre-existing condition is a medical condition that existed before someone applies for or enrolls in a new health insurance policy.

On January 1st, 2014, a part of the [Patient Protection and Affordable Care Act](#) (PPACA; also known as Obamacare) started. This part of the PPACA changed the way insurance treats people who have pre-existing conditions. Insurance companies are no longer allowed to drop patients, raise rates, and offer poor coverage for patients with conditions they consider high risk because of a pre-existing condition. As long as a person pays their insurance bills, the insurance must cover them the same as everyone else.

6 Summary

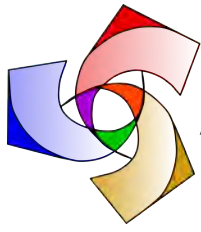
Only people you choose can know about your ASD diagnosis. Your health information is protected by a law called (HIPPA). In very rare cases your information may be shared for emergency medical reasons or due to your medical records being stolen.

It's your choice if you want to tell your new healthcare provider, their staff, or your insurance company about your ASD diagnosis. Telling your provider may help them better understand you and make working with you easier (but some providers may also need some education). It may also be necessary if you want to get accommodations for work.

Your healthcare provider is not allowed to share your ASD diagnosis with your employer unless you give your permission. The ADA protects people

with disabilities from being discriminated against at work. However it also says someone can be fired or not hired because of their disability if it would be unsafe for the person or their co-workers. Seek legal advice if you are concerned about this.

Currently, it is unlikely that you will lose or be denied health insurance coverage because of your ASD diagnosis, but it is possible. However, on January 1, 2014, a part of the [Patient Protection and Affordable Care Act](#) (PPACA; also known as Obamacare) will start. It will prevent insurance companies from denying coverage or dropping patients because of pre-existing conditions, including ASD. Then it won't be possible anymore to be denied insurance or dropped from coverage because an ASD diagnosis.



AASPIRE

Healthcare Toolkit

Your Rights in Healthcare: Equal Access

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Your Rights in Healthcare: Equal Access

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Last Updated September 29, 2015

1 What is this topic about?

This topic is about getting equal access to healthcare. Equal access means having the same opportunity to get quality healthcare as people who are not on the autism spectrum.

The Americans with Disabilities Act (ADA) is the main law that requires equal access to healthcare for people with disabilities, including people on the autism spectrum. This section talks about how the ADA applies to healthcare, how to get accommodations for equal access, and where to find more information about the ADA in healthcare settings.

2 What is the ADA?

The Americans with Disabilities Act (ADA) is a broad law that makes sure people with disabilities are not discriminated against and have equal access to

- employment,
- state and local government services, information, and buildings,

- public transportation,
- privately operated facilities that are open to the public (for example, restaurants, retail stores, hotels and movie theaters, doctors' offices, homeless shelters, and recreation facilities),
- telephone service, including the requirement that telephone companies provide relay service and assistive telecommunications devices for the deaf and hard of hearing.

3 What are "reasonable accommodations"?

Healthcare settings are covered under state and local government services, information and buildings, and under privately operated facilities that are open to the public.

Making healthcare accessible is typically done by providing "reasonable accommodations".

An *accommodation* is a modification or adjustment to something that enable a person with a disability to do something they would not otherwise be able to do.

A *reasonable* accommodation is an accommodation that can be made without causing "undue hardship". Undue hardship is considered "significant difficulty or expense".

Accommodations are not defined in the ADA. It is expected that accommodations will be negotiated on a case-by-case basis. What is "reasonable" is also not defined in the ADA beyond saying it is "feasible" and "plausible" and would not cause "undue hardship." Part of the reason for this vagueness is because what is "reasonable" could change depending on the situation.

An example of an *accommodation* for someone who has a hard time hearing or following quick real-time speech might be hiring someone to provide closed captions.

That accommodation might be *reasonable* if it's requested at a large government-sponsored conference.

But the same accommodation might cause *undue hardship* for a small conference where the cost of hiring someone to provide closed captions would be larger than the entire conference budget.

4 How does the ADA apply to healthcare?

The ADA does not give specific recommendations for how to give people equal access to healthcare. This is because different people have different needs. What helps one person might not help another. Instead the law just requires that facilities and services are accessible, as long as it does not cause "undo hardship." What will cause "undue hardship" will be different depending on where you get your healthcare. For example, a clinic that's part of a large city hospital might have a greater ability to accommodate some needs, for example providing an American Sign Language (ASL) interpreter, than a small, rural practice. A small, rural practice may have a greater ability to accommodate other needs, for example, they may be more able to offer house calls. Healthcare providers may not know about the ADA or understand that it applies to them. Each provider is different, but in general, it is easiest to educate providers about the ADA while discussing your own personal needs for accommodations. Here are some examples of ways that accommodations under the ADA can happen in healthcare. These are just meant to be examples. You might not need these things. Your clinic may also not be able to provide all of them.

4.1 Accessible Buildings / Facilities

The ADA requires that certain buildings (such as state and local government buildings) follow accessibility standards to ensure people with disabilities can

fully access them and the services that happen within them. Most healthcare facilities and buildings are covered under this law. Examples of ways buildings or facilities can be made accessible to people on the autism spectrum are by:

- providing sensory-friendly waiting or examination areas,
- providing maps or assistance navigating buildings,
- making sure mobility devices can access buildings.

4.2 Accessible Communication / Services

The ADA requires healthcare facilities to provide patients and their supporters with services to ensure effective communication between patients and healthcare providers. This includes things like:

- qualified interpreters
- note takers
- real-time computer-aided transcription services or real-time captioning
- written materials
- exchange of written notes
- braille materials
- screen readers
- large print materials

Other examples of ways communication and healthcare services can be made accessible to individuals on the autism spectrum are:

- allowing a service animal or trusted person to be present,
- allowing extra time for communication,

- preparing a schedule of the visit in advance and being communicative of changes,
- requesting healthcare providers use direct, specific language.

The examples given here are just that: examples. If there is something you need in order to make healthcare facilities or communication with healthcare providers accessible to you, discuss it with your healthcare provider. The ADA is open-ended so that lots of different kinds of needs can be met.

5 How do I request ADA accommodations for my healthcare?

If you need accommodations to access healthcare, talk to your healthcare provider or their office staff about your needs.

No one can say for sure how a particular provider will respond to a particular patient's requests for accommodations. However, the following are a few tips that may make your request for accommodations more effective:

- Do not make the request seem like a demand.
- Explain the way(s) that your disability makes it difficult to get good healthcare. Give concrete examples.
- Say that you would like to discuss possible accommodations that could help make visits go more smoothly. (Or that could help you make it to your appointments, or that could help you better follow the providers recommendations, etc.)
- Give some ideas of possible accommodations. Ask if they would be possible or if the provider has other ideas of accommodations that would work well in their clinic or practice.

Sometimes, you may be able to ask for some accommodations before you go to an appointment. Here is an example of a way to request an accommodation from office staff before your visit.

"I am on the autism spectrum and I have a very hard time waiting in busy waiting areas. I get so overstimulated and confused that by the time I go see the doctor, I can no longer pay attention to what he is saying or answer his questions. I would love your help to think about possible accommodations. One idea would be to let me wait in a quiet room until it is my turn. Another would be to let me wait in my car and then call or text my cellphone when it is my turn. Would either of these things work? Do you have any other ideas? I really appreciate your help."

However, more complex discussions of accommodations take time. It is best to schedule an appointment with your provider to talk about a good long-term plan.

Here is an example of a possible way to request accommodations during a visit with a provider:

"I am on the autism spectrum and I sometimes have a hard time with office visits. I often get so anxious or confused that I can't answer questions well or understand recommendations. Could we talk a little about possible accommodations that would make it easier for me to make it through an office visit?" (wait for response.) There are a few things that may help. First, I get really anxious and confused if I don't know what to expect. One thing that might help is to write down a list of things to expect during the visit and then point to each step as we get to it. Is that something that would be possible? Do you have other ideas to help me better understand what to expect during a visit?" (wait for response and discuss ideas)

"Another problem is that I sometimes can't process information quickly. That means that I may not be able to understand what you are saying, think about it, and make a decision as fast as other patients. One idea is to tell me your recommendations, write down the key points, go see another patient, and then come back and let me tell you what I would like to do. Another idea would be to write down the key points, let me think about it at home, and then let me tell you my decision via your secure messaging system. Would either of these ideas work? Do you have other ideas that may help give me extra time to process information?" (wait for response and discuss ideas)

6 What if my healthcare provider does not immediately give me the ADA accommodations I asked for?

Most providers really do want to offer effective healthcare. There may be a number of reasons that a provider does not immediately comply with a request for ADA accommodations:

- They may not understand how your disability affects your healthcare. Try to give very practical examples of how your disability gets in the way of your healthcare. For example, instead of just saying *"I don't like fluorescent lights,"* say, *"I am really sensitive to fluorescent lights. The buzzing and flickering makes it hard for me to focus on what you are saying."*
- They may have perceived your request as an accusation that they did something wrong. Then they may have gotten defensive. It can help if you start your conversation with one of the following sentences to try to set them at back ease:
 - *"I know you are trying to help me."*
 - *"I appreciate your time and your patience with me."*
 - *"I appreciate that you are very busy."*

- *“Sometimes I am very direct, but I would really like to work with you to make visits go more smoothly.”*
- *“I appreciate _____”* (where you fill in the blank with something you honestly do appreciate about your healthcare provider).
- They may not know how to actually give you accommodations. Give them practical examples of what may help.
- They may not be able to do exactly what you ask, and may think that it’s the only option. Make it clear that these are just ideas and you are open to other things that may work better in their practice.
- They may be stressed about time and feel like they don’t have the time to deal with your request for accommodations. Try to make it clear that you respect how busy they are. Work with them to find a better time to talk about your request. Tell them you would like to work with them to find accommodations that can fit into a busy clinic schedule.
- They may get overwhelmed if you make too many requests at once. It is best to highlight just a few accommodations. Focus on the ones you think are going to be more useful.
- They may not be thinking of your requests as ADA accommodations. Many providers think of the ADA as it applies to things like the need for wheelchair ramps, but they may not have ever thought about the ADA as it applies to their own patient care. They may be confusing your requests as “preferences” instead of actual ADA accommodations. Using the word “accommodations” and specifically linking the requests to your disability may help. If not, it may help to educate them about the ADA. But it is best to do so in a non-threatening way. For example, instead of saying, *“The law says you have to give me accommodations,”* you may say, *“The ADA protects my right to have reasonable accommodations in healthcare, and I want to work with you to figure out what would be reasonable in your practice.”*

Getting the right accommodations is likely going to take time. It may take more than one visit to set up the accommodations you need and to find ways to actually make them work. Your accommodations are also likely to change over time. If a provider seems to be open to working with you, have patience and keep trying to figure out what works best. If a provider does not seem willing to work with you, you have the right to go to a different provider. Some providers are never going to work well with some patients. Try to find someone who will.

7 How do I make sure other healthcare providers know about my ADA accommodations?

Encourage your healthcare provider to keep a written list of your accommodations with your records so they and their staff will know your accommodations the next time you need healthcare. You might want to make an Autism Healthcare Accommodations Report for your healthcare provider. Keep a copy of your accommodations report so that you can show it to other providers.

During emergency situations, you might not be interacting with your regular doctor, or you might not be able to communicate your needs. Write down the most important accommodations you need and keep the note in your wallet, bag, purse or something that you are likely to have with you. That way emergency personnel can find it. A PDF form you can download and fill out is available at www.my-healthkey.com.

You may also want to consider getting a medical ID that notes important information about accommodations you need in medical situations. You can get medical IDs online from many places such as www.americanmedical-id.com and <http://www.medicalert.org/>. You can search for "medical id jewelry". Some jewelry stores will also make them. Ask your local jewelry stores.

8 Do I have to tell my healthcare provider about my ASD diagnosis to get accommodations?

If you want to get accommodations under the ADA, you need to disclose your diagnosis to your healthcare provider. This is because the ADA only requires people to make accommodations for individuals who have a documented disability. For more information on how the ADA defines disability see "Are people on the autism spectrum protected by disability rights laws?"

It is sometimes possible to get informal accommodations without disclosing that you have ASD. For example, you might just say, "I have a disability that makes it hard for me to talk on the phone, can we come up with a different way for me to communicate with your office?" Others may be willing to accommodate your needs, and not question why you need them. However, people will not be required to accommodate your needs if you do not share that you have a documented disability. They can refuse and you will not be able to do anything about it legally.

For more information on disclosure see the Disclosure section.

9 Where can I find more information and advice on the ADA?

You can get more information about the ADA, as well as information about other laws that protect the rights of people with disabilities in the section Disability Rights Laws.

Also, here is a comprehensive list of links to resources related to the ADA.

Main ADA page - <http://www.ada.gov>

For more information on the ADA and healthcare - <http://www.pacer.org/publications/ada>
For more a very in-depth legal analysis of the ADA in healthcare, see <http://www.ncbi.nlm>
(note: this article is written in a very academic style)

ADA Centers see <http://adata.org/Static/Home.html>

For a useful questions and answers article on the ADA and healthcare from the Pacer Center: <http://www.pacer.org/publications/adaqa/health.asp>

ADAdata.org has a frequently asked questions page where you can learn more about the ADA. <http://adata.org/faq-page>

Here are direct links to the ADA Centers for each region in the U.S.:

- New England ADA Center - Maine, New Hampshire, Vermont, Massachusetts, Connecticut, and Rhode Island www.NewEnglandADA.org
- Northeast ADA Center - New Jersey, New York, Puerto Rico and the U.S. Virgin Islands www.dbtacnortheast.org
- Mid-Atlantic ADA Center - Delaware, District of Columbia, Maryland, Pennsylvania, Virginia and West Virginia www.adainfo.org
- Southeast ADA Center - Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina and Tennessee www.sedbtac.org
- Great Lakes ADA Center - Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin www.adagreatlakes.org
- Southwest ADA Center - Arkansas, Louisiana, New Mexico, Oklahoma and Texas www.dlrp.org
- Great Plains ADA Center - Iowa, Kansas, Missouri and Nebraska www.gpadacenter.org
- Rocky Mountain ADA Center - Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming www.adainformation.org
- Pacific ADA Center - Arizona, California, Hawaii, Nevada and the Pacific Basin www.adapacific.org
- Northwest ADA Center - Alaska, Idaho, Oregon and Washington www.dbtacnorthwest.org

10 Summary and Tips

The Americans with Disabilities Act (ADA) is the main law that requires health-care settings to be accessible to people with disabilities.

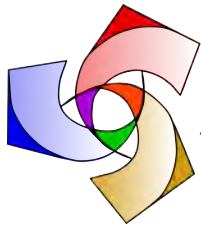
The ADA does not specify how to make healthcare settings accessible but requires that

- Healthcare buildings and facilities are physically accessible.
- Communication with healthcare providers and healthcare services is accessible.
- Modifications to make healthcare accessible do not cause significant difficulty or expense to implement.

Figuring out how to make facilities and communication accessible in a way that works well for everyone is done in a conversation with the healthcare provider or their office staff.

If you need an accommodation for regular healthcare visits, request it from your healthcare provider or their office. For accommodations and communication during emergency situations, carry a note or use a medical ID that has the most important accommodations listed on it.

If you want accommodations under the ADA, you need to tell your healthcare provider about your ASD diagnosis. You may also request accommodations without disclosing your diagnosis, but your healthcare provider or their office may legally refuse your request.



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Healthcare Toolkit

Your Rights in Healthcare: Privacy

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Your Rights in Healthcare: Privacy

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1 What is this topic about?

You have privacy rights under a federal law that protects your health information. These rights are important for you to know. You can exercise these rights, ask questions about them, and file a complaint if you think your rights are being denied or your health information isn't being protected. This section is about that federal law, called the Health Insurance Portability and Accountability Act, or HIPAA. It includes what kind of information is protected by HIPAA and under what conditions your private health information can be shared.

Most of the information in this section was created by the [Department of Health and Human Services](#). It is available in the pamphlet "[Your Health Information Privacy Rights](#)".

2 What is HIPAA?

The Health Insurance Portability and Accountability Act is a federal law that gives national standards for keeping health information private. It is commonly referred to by its acronym, HIPAA.

HIPAA prevents healthcare providers, most health insurance plans, and other healthcare agencies from disclosing your personal health information without your written permission. Health information protected by HIPAA is:

- Anything in your medical record
- Conversations your medical providers have about your care or treatment (for example, conversations your doctor may have with his nurse about your care)
- Information about you in your health insurer's computer system
- Your medical billing information
- Most other health information about you held by anyone involved in the healthcare system

3 Who must follow HIPAA?

- Most doctors, nurses, pharmacies, hospitals, clinics, nursing homes, and many other health care providers
- Health insurance companies, HMOs, most employer group health plans
- Certain government programs that pay for health care, such as Medicare and Medicaid

4 How can I receive a notice about my privacy under HIPAA?

You can learn how your health information is used and shared by your provider or health insurer. They must give you a notice that tells you how they may use and share your health information and how you can exercise your rights. In most cases, you should get this notice on your first visit to a provider or in the mail from your health insurer, and you can ask for a copy at any time.

You may have other health information rights under your state's laws. When these laws affect how your health information can be used or shared, that should be made clear in the notice you receive.

5 Can I see my health records?

You can ask to see and get a copy of your medical record and other health information. You may not be able to get all of your information in a few special cases. For example, if your doctor decides something in your file might endanger you or someone else, the doctor may not have to give this information to you. In most cases, your copies must be given to you within 30 days, but this can be extended for another 30 days if you are given a reason. You may have to pay for the cost of copying and mailing if you request copies and mailing.

6 Can I have corrections made to my health records?

You can ask to change any wrong information in your file or add information to your file if it is incomplete. For example, if you and your hospital agree that your file has the wrong result for a test, the hospital must change it. Even if the hospital believes the test result is correct, you still have the right to have your disagreement noted in your file. In most cases the file should be changed within 60 days, but the hospital can take an extra 30 days if you are given a reason. Your healthcare providers and their staff can share your health information with each other, as well as with insurance companies and others involved in healthcare billing. In general, your health information cannot be given to your employer, used or shared for things like sales calls or advertising, or used or shared for many other purposes unless you give your permission by signing an authorization form. This authorization form must tell you who will get your information and what your information will be used for.

7 Who gets to know about my health information?

Your healthcare providers and their staff can share your health information with each other, as well as with insurance companies and others involved in healthcare billing. In general, your health information cannot be given to your employer, used or shared for things like sales calls or advertising, or used or shared for many other purposes unless you give your permission by signing an authorization form. This authorization form must tell you who will get your information and what your information will be used for.

8 What if I want to share my health information with someone?

HIPAA only prevents unauthorized sharing of your health information. You can give your permission in writing that some or all of your health information can be shared with someone else, usually called a third party. Ask your healthcare provider give you a form to do this. This document authorizes your medical provider to share your medical information with a third party of your choosing. It is important that your medical information only be shared with the people you intend to share it with. Before you sign a form to release your medical records it is important to make sure the form does the following:

- Says how much will be shared - You can share your complete record, just one section or information related to a specific medical problem.
- How often can the information be shared - Will the information be shared once or will information be shared on an ongoing basis? If the information is going to be provided on an ongoing basis then there should be a date when the authorization expires and must be renewed.
- Who will receive the information - This is the person or provider you are sharing the information with (the third party). This should include the person or provider's name, address and telephone number.

- How will it be shared - There should be a place where you indicate how your records will be sent to the third party. In most cases it should be provided by mail or hand delivery rather than faxed to avoid the information being seen by anyone else.

9 Is there a way to know how my health information has been shared?

Under the law, your health information may be used and shared for particular reasons, like making sure doctors give good care, making sure nursing homes are clean and safe, reporting when the flu is in your area, or making required reports to the police, such as reporting gunshot wounds. In many cases, you can ask for and get a list of who your health information has been shared with for these reasons. You can get this report for free once a year. In most cases you should get the report within 60 days, but it can take an extra 30 days if you are given a reason.

10 How else can my private health information be protected?

10.1 Ask to be reached somewhere other than home

You can make reasonable requests to be contacted at different places or in a different way. For example, you can have the nurse call you at your office instead of your home, or send mail to you in an envelope instead of on a postcard. If sending information to you at home might put you in danger, your health insurer must talk, call, or write to you where you ask and in the way you ask, if the request is reasonable.

10.2 Ask that your information not be shared

You can ask your provider or health insurer not to share your health information with certain people, groups, or companies. For example, if you go to a clinic, you could ask the doctor not to share your medical record with other doctors or nurses in the clinic. However, they do not have to agree to do what you ask.

11 How do I file a complaint if I think my privacy has been violated?

If you believe your information was used or shared in a way that is not allowed under the privacy law, or if you were not able to exercise your rights, you can file a complaint with your provider or health insurer. The privacy notice you receive from them will tell you who to talk to and how to file a complaint. You can also file a complaint with U.S. Government. More information on filing a complaint can be found on the [Department of Health and Human Services \(DHHS\) web site](#), emailing DHHS at OCRMail@hhs.gov or by contacting the [regional office closest to you](#).

Region 1 (CT, ME, MA, NH, RI, VT)

Voice phone (800) 368-1019

FAX (617) 565-3809

TDD (800) 537-7697

Region 2 (NY, NJ, PR, VI)

Voice Phone (800) 368-1019

FAX (212) 264-3039

TDD (800) 537-7697

Region 3 (DE, Washington DC, MD, PA, VA, WV)

Voice Phone (800) 368-1019

FAX (215) 861-4431

TDD (800) 537-7697

Region 4 (AL, FL, GA, KY, MS, NC, SC, TN)

Voice Phone (800) 368-1019

FAX (404) 562-7881

TDD (800) 537-7697

Region 5 (IL, IN, MI, MN, OH, WI)

Voice Phone (800) 368-1019

FAX (312) 886-1807

TDD (800) 537-7697

Region 6 (AR, LA, NM, OK, TX)

Voice Phone (800) 368-1019

FAX (214) 767-0432

TDD (800) 537-7697

Region 7 (IA, KA, MO, NB)

Voice Phone (800) 368-1019

FAX (816) 426-3686

TDD (800) 537-7697

Region 8 (CO, MT, ND, SD, UT, WY)

Voice Phone (800) 368-1019

FAX (303) 844-2025

TDD (800) 537-7697

Region 9 (AS, AZ, CA, GU, HI, NV)

Voice Phone (800) 368-1019

FAX (415) 437-8329

TDD (800) 537-7697

Region 10 (AK, ID, OR, WA)

Voice Phone (800) 368-1019

FAX (206) 615-2297

TDD (800) 537-76

12 How do I get more information about HIPAA?

This is a brief summary of your rights and protections under the federal health information privacy law. You can ask your provider or health insurer questions about how your health information is used or shared and about your rights. You also can learn more, including how to file a complaint with the U.S. Government, at the website at <http://www.hhs.gov/ocr/hipaa/> target="HHS";www.hhs.gov/ocr/hipaa/i/a.

13 If I disclose ASD to my healthcare providers, is it covered by HIPAA?

Yes. Your healthcare provider can only share your medical information, including your autism spectrum disorder diagnosis, with other health-related people or agencies for billing, insurance, and treatment purposes. Otherwise, your medical records and information, including your ASD diagnosis, must be kept private.

14 Summary

- The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that provides national standards for the privacy of health information.
- Because of HIPAA, healthcare providers, their staff, most insurance companies, and healthcare-related government programs can not share your health information without your written permission. They are allowed to share it with other healthcare providers involved in your care, for example a doctor can tell her nurse.
- You have a right to request your own medical records and ask for corrections to them. You also have a right to receive a notice explaining how

HIPAA affects you. You can request this information from your healthcare provider.

- If you want to share your healthcare information with someone other than your provider (a third party) you can do so by giving written permission. Ask your provider for a release form.
- If you think a healthcare provider has violated your privacy under HIPAA, you can file a formal complaint. The [HIPAA web site](#) gives information about how to do this.
- Your ASD diagnosis is protected by HIPAA, just like all your other protected health information.

15 Links and Resources

To see the flyer most of this information was taken from download [HIPAA's consumer rights PDF](#).

For more information on HIPAA see:

- <http://www.hipaa.com/>
- <http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html>
- <http://www.cms.gov/HIPAAGenInfo/Downloads/HIPAALaw.pdf>
- <http://www.privacyrights.org/fs/fs8-med.htm>

Your Rights in Healthcare: Decision Making Authority

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www.aaspire.org

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1 What is this topic about?

This topic is about what legal rights you have to make medical decisions. It covers healthcare-related legal documents, state laws about medical decision making, what to do if you disagree with a healthcare decision, and where you can go for help relating to medical decision making.

2 Consent and Self-advocacy in Healthcare

All people are worthy of inclusion and respect. Respectful healthcare does not make people feel bad, guilty, or inferior. It is important that you know your rights and how to advocate for them. There are some situations where your rights may be limited. For example, if you have a conservator or guardian, that person may make decisions about your medical care that you do not always agree with. Or if a professional is concerned that you might be suicidal or dangerous to others, he or she may have the right to take actions you don't agree with in order to ensure your safety. However, in most circumstances, you should not be forced into a healthcare situation without your permission. If you are uncomfortable with a healthcare provider, then you have the right to say "no" to their services and to seek healthcare from someone else. If a professional makes you feel uncomfortable, or does something you feel is

wrong, bring it up to him or her. Make it known that you are uncomfortable and that you would appreciate if they would respect your boundaries and concerns. Your healthcare provider should always be able to explain to you why they are doing something and how it relates to your healthcare. If your healthcare provider cannot respect your wishes, you do not have to continue seeing them and you can look for another provider if it's a bad fit. If you feel you have been treated wrongly by a healthcare provider, two places to try asking for help are:

- Contact your state's [Protection and Advocacy](#) (P&A) program
- Contact the healthcare provider's professional licensing board in your state; for example, search for terms like "osteopath licensing board Arizona" or "family practice licensing board Oregon".

3 What state laws exist about medical decision making?

The laws differ from state to state but most states assume adults can make medical decisions on their own. In some states, having a developmental disability may put into question someone's decision-making capacity. The American Bar Association has [a chart](#) describing each state's default medical decision making law. This chart lists the priority order of decision makers for each state. It also describes the procedure for determining the decision maker if there is a disagreement. The chart also describes the procedure for when there is a disagreement on who is the decision maker. (Note: this chart was last updated in 2009, so some information may be out of date.)

4 Can healthcare providers determine my ability to make a healthcare decision?

Healthcare providers often use an interview and their clinical judgment to determine if someone is able to make a particular healthcare decision for himself or herself. A person may have the ability to make a simple decision, but may not be able to make a more complex decision. Their ability to make a decision may also change at different times. For example, a person who is very ill may be confused one day, but may be thinking clearly another day. Healthcare providers cannot determine if someone needs a guardian. Decisions about guardianship have to be made in the legal system.

5 What happens if I'm unable to make medical decisions and I don't have a legal medical decision maker?

You can name the person you would like to have as a legal medical decision maker using an advance directive. This person would be able to make medical decisions for you if you became incapacitated (unable to make decisions for yourself). For example, they might make decisions if you were in a coma. If you don't have an advance directive and become incapacitated, hospitals follow state laws about who can make healthcare decisions for you. Many states rank possible decision makers (called surrogate decision makers) and mandate that hospitals follow this priority order. The ranking for each state is listed in this [American Bar Association chart](#) (Note: this chart was last updated in 2009, so some information may be out of date.)

5.1 What about domestic partners or close friends?

In most states, domestic partners or close friends are last on the list of potential proxies. In some states, domestic partners and close friends are not

on the list at all. Family members generally have higher priority than friends. If you want to allow your domestic partner or a close friend to make medical decisions for you when you can not make decisions for yourself, you need to name them on an advance directive.

5.2 What about emergency situations?

In emergencies, most states allow medical providers to act without the consent of the patient or surrogate decision maker.

6 What are advance directives and how do they relate to decision making?

Advance healthcare directives are legal documents. They have instructions telling healthcare providers what actions to take or not take when an individual is no longer able to make healthcare decisions for himself or herself. This is usually due to illness or incapacitation. The purpose of these documents is to make sure the patient's medical wishes will be followed even when he or she isn't able to communicate them.

Advance directives are also known as living wills, personal directives, or advance decisions.

The two most common types of advance directives for healthcare are living wills and durable power of attorney for healthcare (or healthcare proxy). Advance directives will only be used if you are unable to make medical decisions for yourself. An individual may have more than one kind of advance directive. You can create these documents with a lawyer. Information about how to get help seeing a lawyer is in the section "Where can I get legal help related to decision making?" Many doctors' offices and hospitals also have forms ready that you can fill out without a lawyer. You can ask your doctor or the clinic or hospital staff for help filling out advance directive forms.

6.1 Living Wills

Living wills outline what types of medical treatments should or shouldn't be performed. These may include (but are not limited to) drug administration, hydration, feeding, or resuscitation and life support decisions. A living will doesn't let you select someone to make decisions for you, only what kind of treatments to give you. For that you need to name someone as having durable power of attorney or guardianship.

6.2 Durable Power Of Attorney for Healthcare (also known as a healthcare proxy)

When you give someone written permission to represent you or act on your behalf in legal matters, it is called giving that person power of attorney. Durable power of attorney for healthcare lets you name someone to make healthcare decisions for you, if you were to become unable to make your own decisions. The person you name as a healthcare proxy can make any healthcare decision that you could make, but only if you were unable to make your own decisions.

6.3 What happens if I don't have an advance directive?

If you do not have an advance directive, hospitals follow state laws about who can make healthcare decisions for you. Many states rank potential decision makers in order of priority. States differ on who they will consider. For example, in most states, spouses and blood relatives rank first while a domestic partner or close friend may be last on the list of potential proxies. In some states, domestic partners and close friends are not on the list at all. The ranking for each state is listed in this [American Bar Association chart](#). (Note: this chart was last updated in 2009, so some information may be out of date.) If you want to be sure that the people you name can make medical decisions

for you if you become unable to make them for yourself, you need an advance directive.

7 What are Physician Orders for Life Sustaining Treatments (POLST)?

A Physician Orders for Life Sustaining Treatments (POLST) documents a patient's preferences for end-of-life treatments. POLST forms are often used when a person is chronically ill or near the end of life. POLST forms are physician orders that can tell other professionals what to do or not do in the case of an emergency. The POLST document can communicate to a first responder that the patient does not want cardiopulmonary resuscitation (CPR), or to be transported to the hospital if they had stopped breathing. If a POLST were not in place, the first responder would be obligated by law to do these things. POLST forms are not only used to limit treatment. They can also document life-sustaining treatments a person wants. POLST isn't available in every state but a growing number of states are adopting them. For information about POLST in your state, see polst.org POLST orders are also known as medical orders on life-sustaining treatment (MOLST), medical orders on scope of treatment (MOST), or physician's orders on scope of treatment (POST).

8 What is the Difference between Advanced Directives and Physician Orders for Life Sustaining Treatments (POLST)?

Advance directives indicate what a person would want IF they were to become too incapacitated to make their own decisions. They are filled out while the person can make his or her own decisions. They only come into use in the future when the person becomes incapacitated. POLST forms are active orders that are in place now. They can be filled out by the person themselves or by their power of attorney for healthcare. For example, someone may say on an

advance directive that if he were ever in a persistent vegetative state (“brain death”), he would not want to be kept alive on a breathing machine. But if that person is at home and suddenly stops breathing, paramedics can’t use the advance directive to decide whether or not to put him on a breathing machine. A person with a terminal cancer may not want paramedics to resuscitate him, even if he is not in a persistent vegetative state. That person may wish to fill out a POLST form indicating that he does not wish to have cardiopulmonary resuscitation (CPR) or be put on a breathing machine. Paramedics can see a POLST form, read the person’s wishes, and not start CPR.

9 What should I know about guardians or conservators?

9.1 What is a guardian or conservator?

A guardian or conservator is someone who can act as the legal authority for another person. A guardian is usually appointed by a court. Guardians are appointed for a number of reasons. If the ward is a minor without parents, guardians are assigned by the courts until the ward reaches the age of 18. Guardians can be appointed for adults as well. This is only done if the ward is incapacitated or someone has decided that their disability makes them unable to care for themselves. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after all other alternatives to guardianship have proven ineffective or are unavailable.

9.2 Is there a difference between a guardian and a conservator?

This depends greatly on what state you reside in. In some states there are few differences but in other states there are many differences. In some states one term or the other isn’t used at all. See your [state resources](#) for more information about guardianship in your state.

9.3 What role does guardianship play in healthcare?

Guardians or conservators are allowed to make healthcare decisions for another person. A guardian may be appointed by the courts if the patient's illness or disability makes him or her unable to make their own decisions.

9.4 What are alternatives to guardianship?

Because having a guardian or conservator takes away a great deal of power from the ward, people often seek alternatives to guardianship. Some alternatives to guardianship might be:

- Representatives or substitute payees
- Case/care management
- Durable powers of attorney for health care
- Living wills
- Financial powers of attorneys
- Personal advocates or supporters

9.5 How can I have guardianship or conservatorship removed?

Guardianship can be removed through a legal process at the court that made the determination.

10 What should I do if I disagree with a healthcare decision a guardian has made for me?

A guardian has a legal duty to act in the best interests of the ward, but there are times when the ward and guardian may disagree about medical treatment.

Disagreements about healthcare can be difficult because in most states the guardianship laws consider the ward unable to make informed healthcare decisions. If you disagree with your guardian about treatment, and the treatment could have a big impact on you, then the courts may need to get involved. The court usually acts as the final decision maker when the ward and guardian can't agree.

10.1 If I have a guardian, is my consent needed for medical care?

No. A guardian is authorized to consent on the ward's behalf. The guardian should take into account the ward's preferences for healthcare providers, treatments, and other healthcare services,. It is appropriate for a guardian to communicate with and seek the ward's involvement and agreement whenever possible. This is called getting the "assent" of the ward."

10.2 Are there any treatments that cannot be forced on me?

There are certain treatments that a guardian cannot force on a ward without a court's consent. For example, treatments that have substantial side effects such as psychotropic medications often require consent from a court. Another example would be major or experimental surgeries.

10.3 How do I petition the court about a medical disagreement?

A petition asking the court to review the guardianship can be filed with the court that issued the guardianship. The court may have a form that you can fill out. The petition can be filed by the you (the ward), your attorney, a family member, a friend, or a supporter. The petition should simply say why you are requesting a hearing. It is strongly recommended that you speak to a lawyer before submitting the form to make sure everything is in order. See

the section on "Where can I get legal help related to decision making?" for more information.

10.4 Are there other alternatives to court proceedings?

Full court proceedings can be costly. Many states have options such as ombudsman programs, or medical or legal advocates that help resolve the disagreement. See the section on "Where can I get legal help related to decision making?" for who to contact.

10.5 What if my guardian and my healthcare proxy don't agree?

When a ward has both a healthcare proxy from an advance directive and a guardian, there is sometimes confusion over who has the authority to make health care decisions on the ward's behalf. Unfortunately there is no easy answer here. It varies by state. See the section on "Where can I get legal help related to decision making?" for more information.

11 Where can I get legal help related to decision making?

The US [Administration on Intellectual and Developmental Disabilities](#) (AIDD) is a government agency that works to support programs that help people with intellectual and developmental disabilities fully participate and contribute to their communities. The AIDD is a good place to start if you are looking for help understanding legal decision making. The AIDD oversees the [State Protection and Advocacy Systems](#) (P&As). The P&As work at the state level to help individuals with intellectual and developmental disabilities advocate for themselves. The P&As are another good resource if you are looking for help. Because they work on the state and local level they are more likely to know of services local to you. Some of the services they provide include:

- Information and referral
- The protection and advocacy of legal and human rights.
- Investigation of into the violation of rights of individuals with developmental disabilities.
- Help to resolve complaints through mediation, alternative dispute resolution and litigation.

Some areas also have legal aid clinics that offer low-cost or free legal help. Law school clinics also sometimes offer free legal advice. There are also some organizations and individual lawyers that do pro bono work (work for free). You can contact your local university or search the Internet to look for these types of services. Note: This information is provided in hopes that it will be helpful. We cannot say whether or not these resources will be able to address your legal questions or issues. We cannot say whether or not you will be able to get the legal outcome you would like. We cannot say whether or not you will receive good legal advice from these sources.

12 Summary

In most situations, you have the right to have a say in your own medical decisions. The situations when you may not have a say are:

- If you become unable to make your own decisions due to illness or injury.
- If a healthcare provider is concerned that you may harm yourself or others.
- If you have a legal guardian or conservator.

If you become incapacitated and unable to make your own decisions due to illness or injury, each state has its own list of who gets to make decisions for you.

- If you would like someone you name to make decisions for you, you will need a legal document called a durable power of attorney for healthcare, which is a kind of advance directive.
- Other kinds of advance directives include living wills, which name the kinds of treatments you would or would not like done if you become incapacitated.
- You can create an advance directive with the help of a lawyer. Many healthcare offices and hospitals can also help you fill out advance directives.

Physician Orders for Life Sustaining Treatments (POLST) give directions to emergency personnel and other healthcare providers about what life-sustaining treatments you do or do not want. If you have a guardian or conservator, they are allowed to make healthcare decisions for you without your consent.

- A guardian may be appointed if you are incapacitated and do not have an advance directive.
- A guardian may be appointed if some process has determined you are unable to make medical decisions for yourself.
- If you have a guardian and disagree with medical decisions they are making for you, you may need the help of a lawyer.
- Some treatments may require a court approval before they can be given to you, even if the guardian wants them done.

The [State Protection and Advocacy Systems \(P&As\)](#) may be a good place to start if you want more information about how to get legal help or better understand laws about medical decision making.

13 Links

13.1 Advance Directives

- [Family Doctor.org](#)
- [The Patient's Rights Council](#)
- American Bar Association links to every state's [advance directive forms](#) (PDF)
- [Caring Connections](#) is an organization that helps individuals access information about advance care planning and care at the end of life. This site has helpful information on Advance Directives and access to Advance Directive forms for all 50 U.S. states.
- Many states have laws that allow Advanced Directives for mental health. The [National Alliance On Mental Illness](#) (NAMI) has information on Advance Directives relating to mental illness.

13.2 Physician Orders for Life Sustaining Treatments

- [www.polst.org](#) has nation-wide information about POLST.

13.3 Decision Making Laws and Priorities

- American Bar Association's [priorities-by-state table](#)
- Information about domestic partners and healthcare decision making from [Unmarried Equality](#)

13.4 State Protection and Advocacy Systems and Other Legal Help

- The US [Administration on Intellectual and Developmental Disabilities \(AIDD\)](#)
- The State [Protection and Advocacy Systems \(P&As\)](#)

13.5 Guardians / Conservators

- General [information about guardians / conservators](#).
- Table of guardian / conservator [laws by state](#)