



# Your Rights in Healthcare: Disclosure

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# Your Rights in Healthcare: Disclosure

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## **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.