
To Disclose or Not to Disclose

Disclosing to Your Teen

There are occasionally circumstances when an adolescent reaches their teen years and is unaware of their diagnosis. This can happen for various reasons. Sometimes they aren't diagnosed until they are older, and other times parents have chosen not to disclose their autism until they feel their child is ready. Regardless of the reason, there are different factors in deciding whether or not now is the right time.

One of the most important factors in establishing whether your teen is ready for their diagnosis is to understand their diagnosis and its impact. However, if your teen has low support needs and the ability to understand, by the time they reach their teen years they may have already noticed that they are different from their peers. In this case, you may feel more comfortable disclosing an autism diagnosis because it can help clarify why they feel different from others and gain a better understanding about themselves.

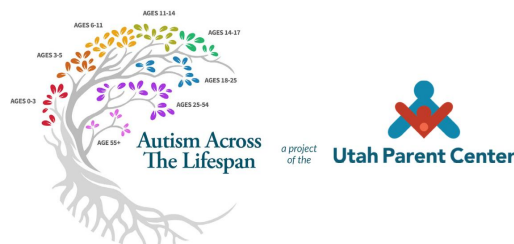
Parent Story

The Benos say that they were so committed to raising Joseph like his siblings that they waited to tell him about his diagnosis. Although many families tell children at a young age, Joseph never asked about his differences, his mother says. And the Benos did not want him to think there was anything beyond his reach. . .

When Joseph was in high school, he joined a different autism study at a university hospital in Dallas. While they were returning from a study appointment, his mother decided it was time. "He was already on track to graduate high school, he was driving, he had a job. And I figured that was a good time to have the talk. So I said, 'Joseph, do you know why you come here and they're studying your brain?' He said, 'no.' I said, 'It's because your brain works a little differently. There are some things that you struggle with, and there are some things you're really good at, and it's called autism.'" Then she told him he did not have to immediately tell everyone at school and at work that he has autism.

"Yeah," Joseph replied. "Because that would be bragging."

"And that's when I knew that I chose the right time to explain it to him," Jeanmarie says."





Disclosing to Family Members

Similarly, by the time your child is in their teen years, their family has probably already noticed that they have different behaviors and needs than a neurotypical teenager. By not disclosing a diagnosis at a young age, you risk their siblings and other family members coming to their own conclusions as to what these differences are. However, some parents believe that if they wait until their child is a teenager to consider disclosing their diagnosis, then they are more likely to be treated like their siblings, cousins, etc. Regardless, if you choose to disclose a diagnosis later in life then the decision is one that needs to be made with your teen. It's crucial that if they have the capability to make this decision that they feel it's their choice.

Disclosing to Friends

As a parent, you might worry that if your teen discloses their ASD diagnosis that they will be outcast by their peers. Making friends in high school is already hard enough without the added difficulties of changing social interactions that ASD teens often struggle to understand. Many teens on the spectrum feel that disclosing their diagnosis to friends gives them a different level of support that is comforting. It can provide an opportunity to "let their ASD out" after being in restricted environments all day. However, there is stigma and misunderstanding with the word Autism and your teen might feel that disclosing this information will make building friendships harder. When your teen is making their decision they should consider how close of a relationship they want or already have, and whether disclosing this information will strengthen this relationship.

Disclosing to School

When your teen transfers to high school you may be wondering whether disclosing an autism diagnosis to the school makes sense, especially if your child has low support needs. To weigh these pros and cons you'll need to consider whether an Individualized Education Program (IEP) or Section 504 plan will help your teen succeed academically and socially. Your teen can help you understand their educational needs and whether they can benefit from an IEP or 504 plan. If there are some areas that your teen needs assistance with, then disclosing to the school will guarantee that they get proper accommodations. Not every ASD teen will feel that they need additional support and services at school. If this is the case with your teen then disclosing may not make sense in this situation.

Disclosing to Work

Many teenagers are excited to get their first job in high school. If your teen has low support needs, then this may be something they choose to do as well. It's important to remember that your teen has the right to keep information about their disability private. There is no

regulation that requires them to disclose their diagnosis. If they choose to disclose to management and the company's Human Resources department (HR), under the Americans with Disabilities Act (ADA), accommodations can be made without the knowledge of other coworkers and colleagues. They may be aware that accommodations are in place but your employer is required by law to keep the reason why confidential.

The type of accommodation that employers can provide to your teen will vary greatly by their individual needs. They might be offered a quiet workspace, specific lighting, breaks, and assistance with understanding tasks. If your teen doesn't feel that they need these types of accommodations, then it's more than possible for them to successfully work without disclosing their diagnosis. Make sure you help prepare your teen for what a working environment will be like and help them understand how to ask for accommodations if needed. If they choose to disclose their diagnosis, have them report the information to their management and HR so that it's on record.

Reference

- Asperger/Autism Network (work)
<https://www.aane.org/disclose-asperger-syndrome-employer/>
- Autism Speaks
<https://www.autismspeaks.org/tool-kit-excerpt/disclose-or-not-disclose>
- Interactive autism network
https://iancommunity.org/cs/adults/deciding_when_to_disclose
- Spark For Autism
https://sparkforautism.org/discover_article/transition-to-adulthood-with-autism/
- The Interactive Autism Network
https://iancommunity.org/cs/articles/telling_a_child_about_his_asd

Resources

- Amazing Things Happen by Alexander Amelines - National Autistic Society, an uplifting introduction to autism for young non-autistic audiences, aiming to raise awareness, understanding and tolerance in future generations.
<https://youtu.be/RbwRrVw-CRo>
- Ask Jan
Askjan.org
- Section 504 Resources
<https://utahparentcenter.org/resources/section-504/>