

Disclosing Their Diagnosis to Support Your Child's Self-Understanding: Caregiver Resource



This resource is part of TRIAD's Self-Advocacy Resource Series. This caregiver resource provides information to parents and caregivers on the process of disclosure and how to talk with their child about their child's autism diagnosis. Please see the "[Four-Step Disclosure Worksheet for Caregivers](#)" which provides a guide for caregivers going through the disclosure process with their child.

WHAT IS DISCLOSURE?

At the most basic level, the dictionary defines disclosure as, "the action of making new or secret information known" (dictionary.com).

In relation to autism, disclosure is the process by which an individual is informed of his/her diagnosis.

WHY IS DISCLOSURE IMPORTANT?

Self-advocate, Armando Bernal states that, “Knowing about one’s diagnosis of autism can shape an individual’s identity from a young age. Disclosure gives the person an opportunity to both understand and accept themselves. The longer you wait to tell somebody about their diagnosis, the harder it will be for that person.”

“In the absence of accurate information, all sorts of wrong conclusions may automatically fill in the gaps, which negatively affects a person’s self-knowledge.”

~Catherine Faherty,
10 Guidelines for Telling Your Child About ASD

This table includes examples across different age and language levels showing the importance of children knowing and understanding their autism diagnosis.

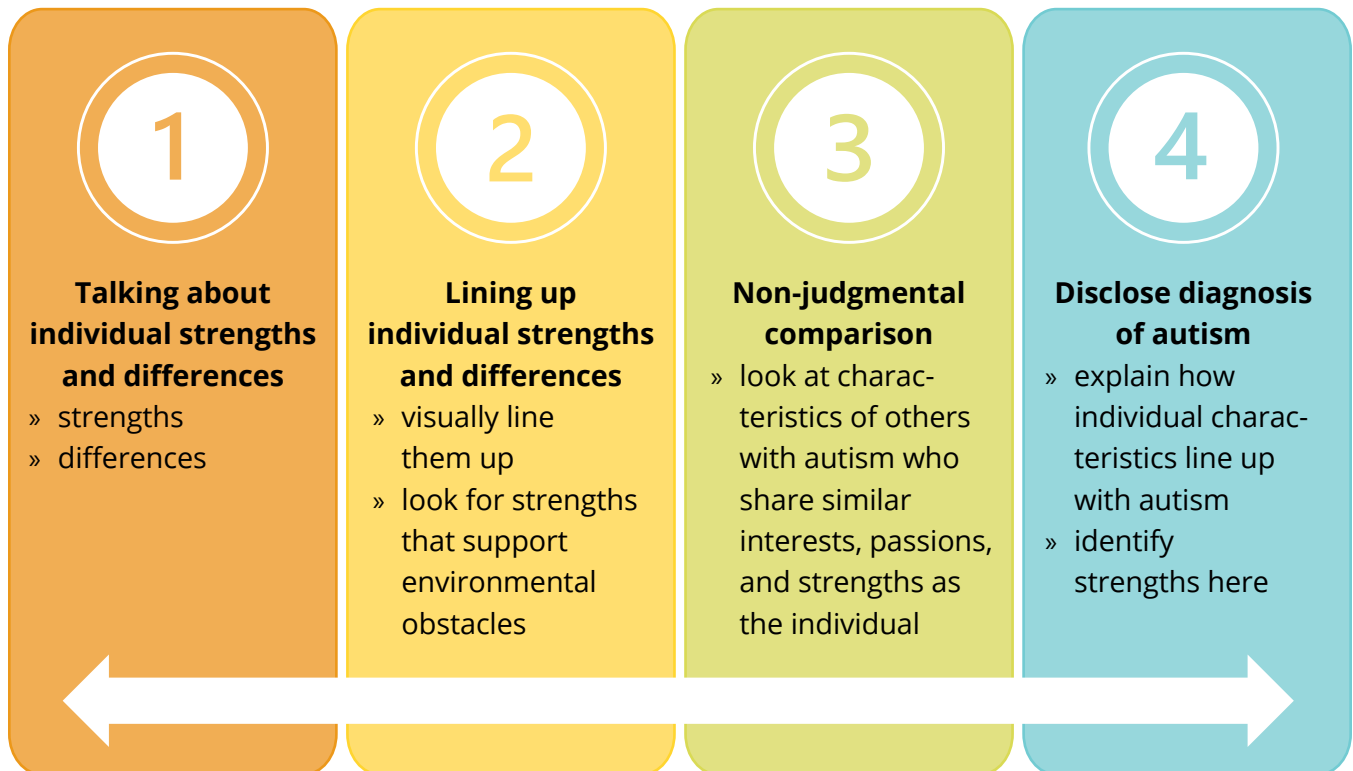
IDENTIFIER	EXAMPLE OF IMPORTANCE
Kindergartner	It is important for Cora to know she has autism in kindergarten, so that she can best advocate for her needs during circle time. For example, she knows that she needs to have space around her and should not be sitting too closely to her friends.
Third Grader	It is important for Liam to know that he has autism, so that he can share that with his soccer team when he is feeling overwhelmed by outside noises.
Middle Schooler	It is important for Lane to know that he has autism in middle school, so that he can take necessary steps to add organization to his locker. Adding additional organizational tools helps him alleviate stress during the class change.
Verbal Student	It is important for Kristin to know she has autism, because although she is quite verbal, she benefits from extended think time on tests. She can advocate for herself on different assignments by requesting more time.
Student with an AAC Device	It is important for Will to know he has autism, so that he can communicate it to his friends using his AAC device. With help, Will can tell his friends that he has special characteristics that make him unique, and can ask his friends about their special characteristics too.

FOUR-STEP DISCLOSURE PROCESS

The Four-Step Disclosure process was developed by Dr. Stephen Shore to assist in sharing the diagnosis of autism with a child or caregiver (Shore, 2006). These four steps allow for a process that is compassionate, planful, strengths-focused, and empowering to the autistic individual.

While this disclosure process may feel overwhelming, it is your role as the caregiver to process this with your child in a compassionate and open-minded way. What better place for your child to discover their unique characteristics than with your affirming support?

What are the Four Steps?



Worksheet:

If you feel that it would be helpful to use with your child, we have included a [worksheet](#) that breaks down the Four-Step Process. Take your time with this worksheet and work at a pace that is determined by your child. This could also be a helpful resource to share with your child's teachers/IEP team.

When working through Step three "Non-judgmental comparison," be especially careful to be judgement free.

"I think it's useful to be candid/honest about one's own challenges, and have a discussion about how everyone has strengths and challenges...no one is good at everything."

~Dave Caudel, Self-advocate

DISCLOSURE CONSIDERATIONS

1

Make sure your child has ownership over the disclosure process.

"It is really important to make sure that the autistic individual has ownership of this process. This is done by asking questions to the autistic individual getting them to come up with the answers. For example, a question to ask the person could be, 'Have you ever noticed that you think about things differently?' Asking questions to help the individual come up with their own strengths and differences rather than you giving them the answers, promotes ownership for the autistic individual." ~Armando Bernal, autistic self-advocate

2

As a caregiver, you can help to empower your young autistic child, by disclosing their diagnosis *with* your child's input. One way to do so is by using sentence frames. Some examples are below:

Your brain works in a way that makes you really good at _____. And it's also the same reason why _____ can be challenging for you. The good news is that we have strategies to help with these things. This also explains why your sister finds _____ easy, while she also finds _____ hard! We all have different brains.

Have you ever noticed that your brain is really good at _____? What are some other things that you notice your brain is really good at? These are things that make your brain unique.

3

Disclosure is a process!

It is important to know that the disclosure process can take place over the course of time and does not have to take place at one time. Depending on their learning preferences and essentials, some autistic students will benefit from this process taking place over several days, weeks, or months.

4

As you work with your child through the disclosure process, it may be helpful to think through times of day where this self-understanding might be important for their learning and engagement in the school setting. Some helpful questions to ask could be:

What setting(s) might be overwhelming for my child?

- Why?
- How can we prepare him/her to self-advocate in these settings?
- How can we support him/her there?

Is there a setting or event where my child will thrive?

- Why?
- How can we prepare him/her for this?

When might my child want to disclose their diagnosis to friends?

- How can we support him/her there?
- What might he/she want to say in this situation?

ADDITIONAL RESOURCES

www.iidc.indiana.edu/irca/learn-about-autism/getting-started-introducing-your-child-to-his-or-her-diagnosis-of-autism.html

REFERENCES

- Shore, S. M., & Joyner, H. R. E. (2004). *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum*. Autism Asperger Publishing, Co.
- Faherty, C. (2017). *10 Guidelines for Telling Your Child about ASD*. <https://catherinefaherty.com/10-guidelines-for-telling-your-child-about-asd/>