AuSM’s highly trained, certified therapists have committed their careers to helping individuals with autism understand their diagnosis and address both the challenges and gifts that it can bring. The AuSM Counseling and Consulting Services team sends out a monthly e-mail to answer questions submitted by the autism community. This is one of the past issues of the column. Visit www.ausm.org to sign up to receive the e-mails.

Dear Dr. Luskin:
I have been hearing the word “ableism” lately and have even been accused of being ableist. As the parent of a child with autism I don’t think I am prejudiced against people with autism, so I don’t really understand this. Can you help me to understand where they’re coming from and how I can respond when it comes up?
– Hurt and Confused

Dear Hurt:
None of us like to hear that our actions are interpreted as harmful to others when we did not intend them to be. As with the recent discussions around racism, it is important to point out that sometimes our actions – often based on habit and unconscious biases – may be inconsistent with other deeply held beliefs. And sometimes those actions do cause harm, whether we intend them to or not.

Ableism is perhaps the newest term to be added to the isms such as racism, sexism, and agism. Like these terms, it means that we assume that the way one particular group (those of European ancestry, men, younger people, etc.) sets the standard is correct. It can include stereotyping against those who are not up to that standard, unconscious assumptions or biases about them, and societal expectations, rules, and systems that provide these people with fewer opportunities.

This can lead people to try to look and act as much like the normative group as possible. Some examples historically have been people of African descent straightening their hair, women wearing power suits, and older women dying their hair or having cosmetic surgery to look younger. Ableism suggests that the way people without disabilities act is the right way and those with disabilities should strive to be as “normal” as possible. Again, historic examples might be the movement to teach deaf children to read lips and speak and to not learn ASL, or, famously, FDR refusing to be seen in a wheelchair and being propped up for speeches so that he could be seen standing.
Ableism even goes further and implies that there is something wrong with disabled people, that they should be valued less than able-bodied and neurotypical people, and that it is the responsibility of the disabled person to fit into society rather than the responsibility of society to accommodate the disabled person.

The problem with ableism is that it gives those with different bodies or brains the message that they are not as good as others. It also pushes them to spend energy trying to look normal rather than moving toward their life goals. It can deny them essential supports and accommodations if those tools don’t help them appear more normal.

In addition to this overarching theme of ableism, another element is that it prioritizes able-bodied and neurotypical people over disabled people. For example you might see stories about disabled individuals that focus on how the disability affects the person’s family or classmates rather than the individual themselves. You’ll often see news stories about disability where no individuals with disability are quoted, while researchers, practitioners, family members, and educators are.

For those with invisible disabilities such as autism, the ableist message can be very subtle. It may start with teaching children that they have to look at others even when this means that they may not be able to hear or process what is being said. It may be denying children (or adults) the access to such accommodations as the use of fidgets or movement breaks because classmates do not need these. It might even be the insistence on placing children in a “normal” classroom when at times they would learn better with focused instruction in a smaller setting. It is the message that you are a burden on those around you, and you need to be better for their sake. Very often intervention programs are designed to teach skills so that children with autism are indistinguishable from peers rather than teaching skills which will help them live the lives that they find meaningful.

Many adults have learned this message and have internalized the value that they need to look like others. We often refer to “masking” one’s autism. Many of my older clients tell me that they do not even know how to stop masking although they find it to be an incredible drain of their energy and it contributes significantly to depression and anxiety.
Ableism may also include statements such as:

- Don’t stim – it makes you look weird
- Grandma hugs and kisses everyone, you just have to deal with it
- Why are you so interested in (fans, obscure music, bus routes, etc) – that makes you sound so weird
- You have to wear "appropriate" clothes, even if they are uncomfortable
- It is not that bright (loud, hot, cold) in here – don’t be such a baby
- Don’t tell people you have autism – they might reject you
- You can’t be autistic – you look so normal (a denial of a person’s own experience)
- You should not ask for services (accommodations, support staff, etc.) – it means you are weak
- There is no reason you can’t work full time – you are just being lazy
- I shouldn’t have to tell you how I am feeling – if you loved me you would know
- You can talk, you shouldn’t use alternative communication
- Don’t spend so much time with other disabled people – you are too normal for that
- You are using your autism as an excuse
- Look me in the eyes when you talk to me

Remember that there are many ways of being and if a behavior does not harm anyone or destroy property it is the right of the individual to decide whether they want to change it or not. At times, acting differently may have social consequences and it may be helpful, in a matter-of-fact way, to make sure the autistic individual knows how “most people” might interpret their behavior.

It is not okay to try to make them change because you will be more comfortable, or even because you think they will be more comfortable or successful. You can offer to help find alternatives to behavior that is interfering with a person’s ability to achieve their goals, but it might be more helpful to help them advocate for what they need from others.

In addition, it’s not ok to think less of them because they continue to behave in ways that you find weird or off-putting.
Remember that this applies to everyone: not just people you know are autistic. If you accept your child with their autistic behavior, but in the workplace you demand that coworkers follow social conventions, you may still have some internalized ableism affecting your behaviors.

To reiterate what I began with, many of us say and do things that are ableist with the best of intentions, because we think it will help someone we care about have a better life.

It’s also important to remember that we all grew up in a society that is ableist and we have received messages throughout our lives reinforcing these beliefs. It takes active work to undo them.

Having your ableism pointed out does not mean you are not a loving parent (or spouse, sibling, friend) or a good person.

It just means that you, like most of us, are still learning how to include individual with different abilities into society in a way that maximizes the benefits for both those who are typical and those that have atypical ways of being, and in the end, society as a whole – since we will all benefit when everyone can use their own talents to the fullest.

– Dr. Barbara Luskin, PhD, LP

If you would like to submit a question for the AuSM Counseling and Consulting Services team, please e-mail autismcounseling@ausm.org or contact us at 651.647.1083.