

The #ActuallyAutistic Guide to Advocacy

Discussion Guide

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Introduction

Thank you for taking the time to read and share this resource with your friends, family, colleagues, and communities! We hope this discussion guide will help you think more deeply about your role as an autism advocate and how you can improve your homes and communities to be more inclusive of all Autistic people. Whether you're an NT (neurotypical) or ND (neurodivergent) parent/caregiver or other family member, friend, partner, educator, autism professional, or self-advocate, this guide will ask you to consider your contribution to the conversation on autism, the treatment of Autistic people, and how you can align your efforts with the desires of the Autistic community.

Each session of the discussion group curriculum corresponds with a "step," or chapter, in *The #ActuallyAutistic Guide to Advocacy: Step by Step Advice on How to Ally and Speak Up with Autistic People and the Autism Community*. Including an introductory session to lay the groundwork for your advocacy journey, there are a total of ten sessions.

This discussion guide can be used as a stand-alone resource for leading group discussions or in conjunction with the reflection questions listed at the end of each chapter in the book. We recommend readers write journal responses to each chapter's reflection questions as a way to digest the advice in stages once they have finished reading that chapter. These responses can be kept as personal reflective material or shared with the group during the corresponding session to enrich conversations about the discussion questions in this guide.

You'll note that, in addition to giving one or more suggestions for all advocates, most sessions also offer three different sets of questions designed for (potentially overlapping) participant roles: NT/ND parents and caregivers; NT/ND professionals; self-advocates.

Depending on the discussion group you are assembling, it may make sense to discuss the questions in only one of the categories or it might be applicable to answer questions from more than one category. We suggest reading through all of the questions, whatever your role(s).

We recommend beginning all sessions with an overview of expectations, including the affirmation that you'll be hosting a safe space for sharing ideas. This means acknowledging that everyone will be at different stages in their advocacy journey, and you won't be judging anyone for their place on that journey or questions they might have. You'll agree to disagree or propose counterpoints in a civil, respectful way, with the understanding that each participant is trying to improve their role as an advocate and that everyone's experiences are valid and should not be dismissed.

We hope your conversations are meaningful and fruitful. We appreciate your partnership in embracing and leading the change necessary to build a more inclusive world.

SESSION ONE: Introduction

Laying the Groundwork

Before we get into the details of inclusive, effective advocacy, we believe there are a couple of things that need to come first. Mindsets and actions that truly advance #ActuallyAutistic goals are fundamentally based on a few key principles, including centering #ActuallyAutistic perspectives, being aware that language evolves, respecting the unique aspects of every human being, and knowing that we all make mistakes. This session, based on our Introduction, asks participants to check in with themselves around these very basic elements of allyship and advocacy.

For all advocates

1. Have you encountered language around autism that caused a strong positive or negative response in you?
2. What are some unique qualities of the Autistic person or people in your life that need to be better honored?
3. What reactions does the idea of centering #ActuallyAutistic voices in your advocacy choices bring up for you?
4. What are some personal implications of participating in a shift toward proactively respecting people of *a//*abilities and neurologies? What do you envision the implications would be for such a shift on a societal scale?
5. What advocacy mistakes have you made that you now know helped you grow?
6. Discuss something you read about in the introduction that you found surprising, interesting, or difficult.

SESSION TWO: Step One

Emphasize Acceptance

Step One is the first step in our first of three advocacy stages. This stage is about the most personal level: building an advocacy base by listening and learning. When seen from a neurodiversity-friendly perspective, most challenges that arise for Autistic people are environmental problems or mutual communication issues, rather than being their “fault.” It naturally follows that we should accept all Autistic people exactly as they are. The question of what sorts of changes in environments and relationships, if any, are necessary to the fulfillment of that holistic acceptance will be tackled later. This session simply gives practical tips that invite participants to prioritize acceptance. We begin to unpack some of the assumptions around autism that may impede acceptance, as well as explore some of the components of genuine acceptance. Here, we frame acceptance as the basis of other important values, and ask advocates to practice it unconditionally—even before learning more about any differences that people might have from one another.

Questions for NT/ND parents and caregivers

1. What parenting/caregiving resources would you recommend that are authored by people from the Autistic community?
2. Some people view autism as a tragedy. Why do you think autism is often framed this way?
3. Why can identifying as an “Autism Warrior Parent” or someone who “battles” or “fights” autism or helps your child “survive in spite of autism” be harmful?
4. What does autism acceptance look like?
5. How do we make sure we are helping our children follow the life path that’s best for them and not the agenda that we have for them (or what we think is best because it worked for us)?

Questions for NT/ND professionals

1. What professional-oriented or other resources would you recommend that are authored by people from the Autistic community?
2. What are some common behaviors that educators and/or autism professionals try to correct or eliminate and why?
3. What responsibility (if any) do educators and/or autism professionals have to teach parents, students, or clients about autism acceptance?
4. How can people facilitate inclusion by ensuring they are meeting Autistic people's needs while also not putting too much pressure on them to do all the work?

Questions for ND self-advocates

1. What resources would you recommend that are authored by people from the Autistic community?
2. Where have you seen Autistic voices dismissed or silenced?
3. What platforms welcome and celebrate Autistic voices?
4. Are Autistic people treated as autism experts in your community? Explain.
5. Has autism advocacy become too political?

For all advocates

1. Do you agree that acceptance should come first, before awareness, research, etc.?
2. What are some ways to advocate for acceptance? Have you experienced any successes in this area?
3. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION THREE: Step Two

Adopt a Balanced Perspective

Our second step counsels us to have a comprehensive, balanced view of neurodivergence. This entails several key aspects, which, together, create an inclusive, non-stereotypical view of Autistic neurodivergence: avoiding assumptions about savantism, including all ages and genders, and being aware that we all have unique strengths and weaknesses. Here, we learn how to avoid generalizations on several levels and proactively nurture a holistic view of both Autistic people and Autistic neurodivergence. To that end, Step Two asks us to closely examine several ways we can broaden our perspectives and grow to be more aware and welcoming of all expressions of autism.

Questions for NT/ND parents and caregivers

1. How have stereotypes about autism impacted your child or other Autistic people in your life?
2. How does your community support/include (or not support/include) Autistic people over the course of their lifespan?

Questions for NT/ND professionals

1. What responsibility do educators and autism professionals have in offering a balanced portrayal of autism to their students and/or clients (discussing the positives and the negatives that come with a diagnosis, for example)?
2. What are the messages about autism within your profession and where do they come from?
3. What services exist in your profession to support/include Autistic people over the course of their lifespan?

Questions for ND self-advocates

1. Discuss the potential problems with promoting autism messaging that is either all positive or all negative.
2. How have stereotypes about autism impacted your school, work, or social experiences?
3. How difficult or easy has it been to meet your needs and achieve your goals in your school, work, and/or community?

For all advocates

1. Discuss autism representation in the media. How do you see autism portrayed on TV, in film, in books, etc.?

2. What have you learned or experienced about perceptions of autism in biologically born females?
3. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION FOUR: Step Three

Assume Competence

In Step Three, we practice extending the basic courtesy of presuming that each of us has certain rights to self-determination and to developing—at our own pace—the capacities needed to exercise those rights. To build a foundation for this stance, we start by distinguishing between autism and other differences, including intellectual disabilities and mental health challenges. We take in the fact that most tests and evaluations are based on neuro-normalized methods that judge Autistic people by standards they may not value or aspire to, while failing to measure other potentially worthwhile qualities. Finally, we practice two crucial elements of assuming competence: we engage in active and patient listening, and we avoid over-sheltering.

Questions for NT/ND parents and caregivers

1. What stereotypes have you encountered around speaking or nonspeaking Autistic people? What are the impacts of these stereotypes?
2. What are some of the biggest fears parents have about their child's future? In what ways can the Autistic community help parents manage those fears?
3. How can parents find a balance between protecting/sheltering their Autistic children and encouraging safe growth?

Questions for NT/ND professionals

1. To what extent is presuming competence discussed in your professional training?
2. How does your profession incorporate Autistic expertise into best practices for serving students, clients, etc.?
3. How does your profession rely on neuro-normalized methods of evaluating competence? What can be done to ensure equitable assessments and outcomes for Autistic people?

Questions for ND self-advocates

1. How have you been underestimated? If so, have you ever been over-sheltered because of that?
2. Who in your life has demonstrated faith in your value and potential? How can your advocacy efforts help others find people like this?
3. What laws or policies are unfair to Autistic people?

For all advocates

1. What are some distinctions between autism and other differences, some of which are often wrongly associated with neurodivergence?
2. What are some of the challenges of active listening, and how might you address them?
3. What weight should be given to neuro-normalized tests when given to Autistic people?
4. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION FIVE: Step Four

Advocate for Individuals

When we decide to become advocates or allies, our enthusiasm for promoting a “cause” can sometimes get in the way of genuinely inclusive, respectful mindsets and actions that take each and every Autistic person as both whole and unique. But we can and should shape our advocacy to integrate the human being(s) at the center of our efforts. Some ways to advocate and ally with individuals include limiting any public sharing to posts, stories, and statements that honor the “do unto others rule” (and always getting permission to share), avoiding making blanket assumptions, and getting to know a person first before attempting to institute any sort of solution. Indeed, in this step, we caution advocates not to assume a solution—especially one based on NT values—is needed or wanted. Here, we find ways to honor the diverse aspects of Autistic people, and create space for their/our qualities to be expressed according to their/our own values, needs, goals, and desires.

Questions for NT/ND parents and caregivers

1. Have other parents/caregivers of NT children tried to give you parenting/caregiving advice for your Autistic child? What was that like?
2. How do you describe your Autistic child to others? What are some ways to discuss your child without using severity labels?
3. What kinds of parent/caregiver advocacy have you seen that make you uncomfortable?

Questions for NT/ND professionals

1. How do you communicate with parents/clients that Autistic people are individuals and it’s difficult (and often incorrect) to generalize about behaviors and needs? If you don’t communicate this, what opportunities exist for this messaging?
2. What examples of inspiration porn have you seen circulated at your work or school, or among autism professionals?
3. How does your profession embrace the individuality of Autistic people? Or how does it rely on stereotypes, if applicable?

Questions for ND self-advocates

1. In what ways have you felt like some of your struggles have been minimized/overlooked/dismissed? What about your strengths?
2. What kinds of autism advocacy behaviors have you seen that make you feel uncomfortable?
3. What do you think about self-diagnosis? What barriers exist to obtaining a clinical diagnosis?

For all advocates

1. What does truly respectful public sharing (on social, in interactions) entail on an interpersonal level? What about when advocating for cultural or societal change?
2. Have you ever offered or been offered a “solution” when one might not be wanted or needed?
3. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION SIX: Step Five

Advocate for Things Autistic People Actually Want

In the second stage of #ActuallyAutistic advocacy, we explore how to integrate #ActuallyAutistic advice into your own ND family, classroom, or practice. Autistic people are as different from one another as any group of humans that share one trait. But, as Step Five counsels, many nonetheless agree it's time to shift our ways of supporting Autistic people toward new, Autistic-informed approaches. Some central areas of concern include school accommodations, therapeutic interventions, relationships, and workplaces. From supporting and implementing only Autistic-initiated therapies to celebrating and respecting diverse relationships, from using the preferred language of each person (person-first or identity-first, for starters) to understanding the social model of disability, autism-friendly home, school, and workplace advocacy is grounded in respecting what Autistic people themselves want.

Questions for NT/ND parents and caregivers

1. How do/can you help support goal-setting for your children (both young and older)?
2. What relationships in your family and social circles might be viewed as unconventional? How have these relationships been beneficial?
3. What ways can parents encourage and support their children to form healthy relationships?
4. What benefits and drawbacks are there to viewing autism under a social model of disability lens?

Questions for NT/ND professionals

1. Discuss the goal-setting process within your profession. Who all is involved and at what stages?
2. Does your profession have standardized ways of talking about autism and envisioning life outcomes for Autistic people?
3. Are there situations where your profession encourages masking? How/why is that implemented?
4. How does your profession view the social model of disability? What is your perspective?

Questions for ND self-advocates

1. If relevant, discuss your process in the pursuit and implementation of therapy. What has gone well? What has gone poorly?
2. Do you have any relationships that might be viewed as unconventional? Where/how did you meet your closest friends?

3. Do you use identity-first or person-first language? What other important things should people consider when talking about autism?
4. What do you think about classifying autism under the social model of disability? What are the benefits and drawbacks to this?

For all advocates

1. Do you think mainstream opinions on neurodiversity and related topics (such as masking, therapeutic interventions, self-diagnosis, intersectionality, and accommodations) are changing? How so?
2. Are there times when an NT opinion should outweigh an ND one? How about the opposite?
3. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION SEVEN: Step Six

Stay Centered on the Autistic Person's Needs and Dreams

NT culture holds a lot of standards and values that may be invisible and/or irrelevant to many Autistic people. A lack of interest in or ability to conform to societal norms (such as gender, hierarchy, etc.) is pretty common in this population. Step Six asks us to remember that different perspectives can also be equally legitimate for the people who live them. So if you are advocating for someone else, make sure it's *their goals and desires* you're advocating for, not yours or society's. In this regard, it can be helpful to listen to Autistic people over NT parents, teachers, and other "experts." And if you're advocating for yourself, know that your needs and dreams are absolutely valid and worthwhile. In this session, we practice focusing on the real needs and dreams of Autistic people, each of whom has their own vision for their best life and goals for how they want to express themselves and achieve success.

Questions for NT/ND parents and caregivers

1. How do you encourage or support autism neutrality in your own home?
2. Have you seen an emphasis on good intentions (either yours or someone else's) get in the way of healthy advocacy?
3. Are you more likely to listen to NT parents and "experts" than your own child(ren) or other Autistic people?
4. How do you distinguish between meltdowns and tantrums in younger children? How do you advocate for your children to prevent meltdowns?
5. How have you given your child increasing levels of independence and nurtured their unique dreams for their life? Discuss the difficulties and celebrations related to this process.

Questions for NT/ND professionals

1. How does your profession encourage and promote autism neutrality?
2. What benchmarks does your profession use to measure success? In what ways does this make sense (or not make sense) for Autistic people?
3. How does your profession support families and Autistic people to pursue varying levels of independence?
4. Is there space in your professional practice to make room for goals and dreams that might not fit the NT norm?

Questions for ND self-advocates

1. For people who are struggling under the weight of everyone else's expectations for their future, how can they advocate for what they believe is best for themselves?
2. How do you self-advocate to prevent meltdowns or shutdowns? If in the middle of a meltdown/shutdown, how do you calm down in overwhelming situations?
3. How were you given/how did you achieve increasing levels of independence? Was there anything frustrating about this process?
4. How were your unique life dreams nurtured as you've gotten older?

For all advocates

1. Are there any Autistic-driven ways of thinking or living that you've experienced or observed that could create positive shifts in the neurotypical mainstream?
2. Are all life goals valid? Why or why not? If possible, give examples to support your point of view.
3. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION EIGHT: Step Seven

Include All Autistic People

Here's where we bring some of the earlier steps around inclusive principles and perspectives on *who's* Autistic and *why* we listen to a range of Autistic viewpoints into a proactively comprehensive stance on advocacy. In Step Seven, we practice deferring to Autistic people as the experts on autism. We honor the authority and basic human equality of all Autistic people of varying skills sets. And we bear in mind that while one particular Autistic person may have unique neurological and personal characteristics, they may nonetheless have broadly useful insights. Here, we underscore the notion that listening is a vital skill for any advocate or ally—and that being heard and seen matters deeply to most Autistic people.

Questions for NT/ND parents and caregivers

1. Where do you get information about autism? How do you incorporate Autistic expertise into your parenting/caregiving?
2. Do you find yourself or other parents/caregivers using severity labels to describe Autistic people? What are the benefits and drawbacks of using severity labels?
3. Discuss some positive ways you've seen people talk about their Autistic children.

Questions for NT/ND professionals

1. How do you incorporate Autistic expertise into your work? How have you sought out a variety of different Autistic voices?
2. What kinds of autism labels are used in your profession? How do the labels encourage stereotyping? Do you use labels that don't encourage stereotyping (or have practices in place that deter stereotyping)?

Questions for ND self-advocates

1. How have you seen autism severity labels used around you? What autism labels (if any) do you use? What do you think about the ways people tend to categorize autism?
2. Have people ever told you that your opinion on autism doesn't matter because you present (or do not present) in a particular way?

For all advocates

1. What are some positive and negative aspects of the "spectrum" model of autism?
2. Have you ever underestimated someone because of their neurological differences?
3. Is genuine equity possible for people of all neurologies? What would that look like?

4. Have you ever had a hard time listening to an Autistic person (or being listened to), or struggled with giving them credence (being given credence)? If so, why?
5. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION NINE: Step Eight

Connect Respectfully With Actually Autistic People

The third stage of #ActuallyAutistic advocacy encompasses public advocacy for autism understanding and acceptance. In Step Eight, the first in this stage, we take our knowledge and inclusive mindset into the public sphere. How? Start by reaching out to the Autistic community, whether online or in person, in meetups or through friends or colleagues. A friendly, open, curious learning mindset can create a lot of opportunities! And if you want to advocate in a public space or work with/educate people about neurodivergence, avoid limiting your pre-advocacy research to just one group or type of Autistic people. Instead, include multiple genders, support needs, speaking or nonspeaking abilities, ages, ethnicities, backgrounds, and so on. And always be aware of the global, national, local, and personal intersections of race and disability and LGBTQIA+ and other marginalized identities. At the same time, it is extremely important to treat Autistic people as people, not study subjects or lab objects, so conduct any outreach or research with care and respect. Finally, ensure that any organizations you support, work with, or work for are truly autism-friendly.

Questions for NT/ND parents and caregivers

1. What kinds of autism research do you read about and share? Who is publishing it? How can people ensure the research they are sharing is promoted/endorsed by the Autistic community?
2. What books written by Autistic people (and, if fiction, featuring Autistic characters) have you read?
3. Do you make an effort to share diverse, intersectional perspectives and stories with your child(ren)? Why or why not?

Questions for NT/ND professionals

1. What kinds of research inform how your profession engages with Autistic people?
2. How does your profession study, understand, and address the intersections of race, gender identity, and disability?
3. Have you witnessed educational, research, or other efforts that treat Autistic people as objects of study rather than full-fledged subjects?

Questions for ND self-advocates

1. What kinds of autism research do you find beneficial? What kinds of research are harmful?
2. What organizations do you find autism- or disability-friendly and why?

3. What aspects of intersectionality do you experience and how do they impact you?

For all advocates

1. What does a genuinely autism-friendly organization look like?
2. In your experience, how is autism framed in public spaces and mainstream perceptions? Any ideas for effective ways to counter the negative portrayals and nurture the positive ones?
3. How can we create public spaces and cultures that uplift and amplify intersectional Autistic perspectives?
4. Discuss something you read about in this step that you found surprising, interesting, or difficult.

SESSION TEN: Step Nine Put Theory into Practice

In this final session, we explore how to continue your advocacy journey in the most beneficial way for all. If you've gotten this far, you've likely learned enough to now become a continual student and implement the knowledge you've gained on an ongoing basis. You've learned to listen and thoughtfully integrate what you hear, and you've learned to act in ways that are respectful of all neurologies and ways of being. And you know that when you're out in the world, opportunities will always abound to listen and grow even more. One way to do this is to stay on top of technology trends, so that you can do your part to make sure people of all neurologies can communicate and succeed according to their own needs and abilities—and on their own terms. Best practices for speaking about neurodivergence, disability, and intersectionality are another thing to watch closely. Finally, Step Nine asks us to continually take responsibility for our mistakes and then move forward, evolving daily toward our most effective, inclusive selves.

Questions for NT/ND parents and caregivers

1. What kinds of AAC or other technology has your child found to be useful?
2. What obstacles have you encountered to accessing or implementing AAC or other technology?
3. How can parents learn to acknowledge and accept past advocacy mistakes and move forward? What are the challenges to doing this?

Questions for NT/ND professionals

1. What kinds of technology does your profession implement that you have found successful?
2. Do you think your profession is evolving in some ways (for example, vis-à-vis language or inclusion)?

Questions for ND self-advocates

1. How can we encourage more action on the advocacy front (rather than only listening to/engaging with other advocates)?
2. What is the advocacy and self-advocacy climate like for those in the public eye? How can we be more welcoming to people in this space?

For all advocates

1. What would you most like to change in the mainstream NT world?

2. Is there anything related to autism advocacy or allyship that didn't come up over these ten sessions that you'd like to discuss?
3. How do you learn best? What is your most effective and comfortable way of sharing what you've learned?
4. Discuss something you read about in this step that you found surprising, interesting, or difficult.

Thank you for participating!

Warmly,

Jenny and Jenna