

SELF-ADVOCACY Toolkit

from the **Lifespan Toolbox**

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ABOUT THE LIFESPAN TOOLBOX

The Lifespan Toolbox consists of toolkits for each topic area important to the lifespan, particularly preparing for and navigating adulthood. This information is applicable for those who have a younger child on the autism spectrum, teens, and adults. In our experience, it's never too early to be thinking about adulthood.

We've collected research, lived experiences from autistic people (the majority of whom prefer identity-first language) and others supporting them, our professional experience serving the community, and combined it into interactive web pages + PDFs to easily download and share.

Keep an eye out for the symbols below for helpful tips related to each role:



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For more information please visit Autism Grown Up at www.autismgrownup.com

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OVERVIEW

Self-advocacy is one of those hidden skill areas that does not always get emphasized as a vital skill. However, in reality, self-advocacy is a major part of growing up and having a life that is meaningful. Self-advocacy overlaps with every skill in focus for autistic individuals - and it is also a need for neurotypicals to learn as they grow up too.

Now, what is self-advocacy? It is a collection of actions that center around one's autonomy. When we talk about self-advocacy in adulthood, we usually hear about advocating for accommodations at work and school and self-disclosure or transferring advocacy from parents and caregivers to the individual. But there are a lot of related areas of note in regards to self-advocacy, such as making choices, decisions, navigating conflicts, self-awareness, and empowerment. We will be covering these areas and how to support them or receive support from others.

In this Self-Advocacy Toolkit, we'll be focusing on what self-advocacy looks like as well as discussing some of the needs in the autism community. Each individual is in a different place and can benefit from learning about ideas and ways to support or seek support. For some, self-advocacy may not be top of mind, and others may find it overwhelming at times. This is where learning about self-advocacy, blending strategies to support the person and meet them where they are, and incremental steps each day can contribute to getting comfortable with making decisions and advocating for themselves. Self-advocacy is a skill that can be learned at any point in one's life.

The Toolkit is for Self-Advocates, Family Members, Professionals, and Community Members to get on the same page and collaborate.

In whatever role(s) you occupy, you can use this guide to support your knowledge on the topic, share information with others in your support networks, and use this in discussions about self-advocacy.

LET'S FOCUS ON

We'll start on a few key areas of importance and frequently asked questions. We will further clarify questions about self-advocacy, address misconceptions, and provide some ideas for further discussion with others via the role you occupy.

Research in autism has primarily focused on struggles and lack of support for autistics in developing self-advocacy skills. It has been found that their parents/caregivers' expectations and attitudes of their child's self-advocacy skills are highly influential of their child's actual self-advocacy skills and related outcomes. The same is true of other adults in the individual's life from teachers, staff, and therapists. Self-advocacy is a predictor of employment, education, independent living, and other adulthood outcomes.



"There is mounting evidence that self-advocacy, determination and including autistic individuals in the educational discussions and research about them leads to positive outcomes that include achieving academic goals, independent living, improved confidence and employment outcomes.

Zuber & Webber (2019)

Click here to read the research on this topic

Note that self-advocacy and self-determination are terms you will see used interchangeably. From what we understand, self-determination is an internal practice of autonomy, self-regulation, psychological empowerment, and self-realization; and self-advocacy is the external and active practice of these components. For the purposes of this toolkit and the spirit of being actionable, we will primarily use self-advocacy as a term.

How can we even get started?

No matter the age of the individual, there's always a place to get started and room to provide opportunities. Self-advocacy is an individualized practice, where you need to start with the individual and proceed from there.

All of these practices are age-appropriate. Self-advocates - you can try these for yourself and offer this list to your support network.



Informal + Everyday

In comparison to political or formal, these tend to get overlooked - but they are the cornerstones to future self-advocacy and tend to be made for autistics instead of with them.

- **Choices**

  Incorporate into different parts of the day. Examples: choice of time leisure activities, making choices for clothing (informed choices are a great opportunity here based on the weather).

- **Decisions**

  About the schedule, coordinated activities, social experiences, being out in the community.

- **Navigating Problems**

  Before they arise, as they are happening, and afterwards to debrief. Working together through problem-solving can also support your relationship!

- **Learning Needs + Strengths**

  Helps build self-awareness and self-realization; changes with skills, settings, and different people.

What are some tips to promote self-advocacy?

Jumping off of the previous question, we're going to delve into specific settings and highlight some tips across each setting. They are applicable across all ages - except for the one about preparing for the transition after high school. But we like to say it's never too early to be thinking about what these could look like!

At Home

- Self-advocacy interlinks with life skills and independence. With chores, habits, and routines, how can you build in a time for questions, asking for help, teaching and giving the space to figure out the life skill?

At School

- This one overlaps with home too, but asking for help is also a big skill to promote, as well as asking for a break for X or Y reason.



- Knowing when to apply coping skills and asking for the space to do so is part of this too.

IEP and other Services

- We don't see a lot of autistic students participate in their IEP meetings. How can we change that? So that they can work towards attending and participating by the time they reach 14? (absolutely required at this age)

After High School

- Related here to the IEP, the student's transition plan should have a lot of their input. It should have their transition assessments - which include information they have provided about their postsecondary goals and interests - in addition to transition programming targeting these goals.

What should I know about self-disclosure and requesting accommodations for self-advocates?

Again, we're going to review our suggestions by setting and outlining some frequently discussed areas around self-disclosure and requesting accommodations.



School and College

While receiving special education services, the student's Individualized Education Plan (IEP) or 504 plan outlines what accommodations they require across settings, including general education and inclusive settings.

After they graduate from high school, and if they decide to attend a postsecondary education setting, the game changes. Setting up accommodations with the Accessibility Services Office falls on the autistic individual, they are the ones that have to coordinate services and ask for accommodations from their professors. Students are less likely to be prepared for this scenario after high school.



The Workplace

Just like with postsecondary education, autistic individuals must self-advocate for their accommodations and they get to decide if they want to self-disclose. This is optional too, and there is a lot of discussion around this topic in the ASD community. There is a huge need for more understanding and positive attitudes in the workplace around accommodations.



STRATEGIES

Here are some starter strategies depending on where you are with self-advocacy:

1. **Understand the power of your expectations.** This note holds true across all of the groups we're talking to in this toolkit. We want self-advocates and family members to internalize this, and they are largely influenced by professionals and the community.

You have so much power. Understand that!
Autistic people are so incredibly resilient and capable of so many things.



2. **Keep Practicing!** You can use so many different tools that apply to your strengths. You can create scripts, visual supports, and stories to describe how you perceive a situation will unfold, outline alternatives, and coping techniques to help destress and de-overwhelm.

Some examples of what these visuals could look like: physical (pen and paper, remember that?!), notes on your phone, texts to yourself



3. **Seek out other self-advocates online.** Visibility helps! Just like with discussions about diversity, representation matters. The same is true for neurodiversity and seeing other autistic individuals who are sharing their experiences online.

Look to other self-advocates for

- Finding self-advocacy inspiration
- Seeing the realities of the challenges of being your own self-advocate and dealing with ableism and people who don't understand
- Appreciating and feeling connected about the hard times
- Feeling connected about the great times and wins

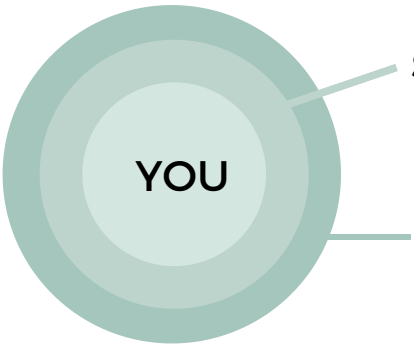


SUPPORT

Here is some starter support for us around self-advocacy.

Connect Online + In Person

Reach out to communities online and in person. Remember that you can take this one step at a time, and that you can bounce ideas off of others in your support network too.



SUPPORT NETWORK

Family, friends, others you go to for support (neighbor, coworker, etc.)

OUTSIDE COMMUNITIES

(LOCAL + COMMUNITY)



This is where there can be tremendous gaps for the ASD community. How can you help connect and build bridges here?

With Autism Grown Up

This is just the start of the conversation, and we invite you to continue this within our Facebook group. This is a space where you can post your questions, share ideas, and chat things out.

Within the group you can link up with members of our community and locally to you.

This hive mind may be just what you need to get answers and support you need to get started and work through obstacles as they arise.



FOR MORE INFO

KEY

BLOG | RESOURCE PAGE | PODCAST | RESEARCH | ARTICLE

Self-advocacy and self-determination of autistic students: a review of the literature
Advances in Autism
By William James Zuber & Colin Webber
READ MORE →

A Self-Advocate's Guide to Managed Long-Term Supports and Services
Autistic Self-Advocacy Network
READ MORE →

Self-Advocacy
By Dr. Stephen Shore at the Autism Research Institute
READ MORE →

***trigger warning for the logo for this site; however, Dr. Stephen Shore is an amazing autistic self-advocate with very insightful writing in this post**

Developing Self-Advocacy Skills to Last a Lifetime
CAR Autism Roadmap from the Children's Hospital of Philadelphia
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www.autismgrownup.com

hello@autismgrownup.com

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