The Autistic Self-Advocacy Support Guided Learning Path

You're disabled, you need support and accommodations, but part of your disability is not actually knowing what support and accommodations you need.

So you search for help. But find none because no one else has a clue either.

Not your medical doctors, not your psychologist, not your educational institution or workplace, and not even family members (parents, spouses, adult children, other loved ones) who desperately WANT to help you.

This is basically where most late identified neurodivergent people find themselves after discovering their neurodivergence.

And I know the feeling painfully well because that was exactly where I found myself several years ago after learning about my own neurodivergence (I discovered sensory processing disorder first, then autism).

But something happened after that...

I started figuring things out on my own. I started developing strategies for myself... I started developing strategies that I could use to get support for my kids (as they moved through elementary and middle school)...

And I started sharing some of those strategies on here as I became a more vocal advocate within the autistic community.

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6 years later, I now have numerous fully formulated strategies, many of which I have already shared with you all... but there's one strategy in particular that I want to talk about today, because it sits at the very heart of the issue I mentioned at the beginning of this post...

How to self-advocate.

Not just *why* you should and *that* you should (which is how I've seen it discussed in most contexts)... but step-by-step guidance for HOW to self-advocate.

More specifically...

- How to ask for things you don't even know you need

- From people who don't know how to help you 😬

Because how do you ask for help when part of your disability IS THAT YOU NEED HELP ASKING FOR HELP?

Am I right? 😅 🤦

And that brings me to the reason for this post. I'm going to walk you through my framework for *how* to self-advocate.

I call it the Autistic Self-Advocacy Support framework.

It's a step-by-step process and guide that has hand-holding literally built into it... to help you figure out what support or accommodations you need *before* you seek them out.

Because if you ask for help from people who don't know what help to give... even if they WANT to help... you both end up looking at each other completely bewildered going "who's on first again?"

So, in other words, you need *help* asking for help...

And this framework IS that help...

Because it will teach you the *skill* of asking for help as a disabled person with support needs.

Because that's exactly what it is... a skill... that can be learned... IF you are taught it.

And that's exactly what I'm about to do. Teach it. 😊

A quick note for parents and caregivers before I continue...

This framework is designed to be used by parents and caregivers as well. I call it a "self-advocacy" framework because even when the process is being directed by a support person, self-advocacy should always be at the center of the work.

More on this later, but please hold onto this thought because it will be a crucial component of the preparation stage of the self-advocacy process for support people.

Now, I'm going to go through the full framework in detail (all in one post so you don't have to go searching for pieces of the framework in different places)...

But first, I'm going to outline the high-level steps so you see the big picture and how it all fits together.

(Also, so you are aware, from an autistic learning perspective, this is context setting, referred to as whole-to-part learning, which is considered the optimal approach for autistic brains to learn new things 😊)

Ok, so... here are the high-level steps of my Self-Advocacy Support framework.

Framework outline...

STAGE 1: PREPARATION – BEFORE REQUESTING SUPPORT

1. Identify your underlying unmet need(s)...

This is whatever is missing from your environment that's causing your challenges (don't worry, the framework will walk you through how to do this).

2. Identify the correct self-advocacy support strategy...

During this step you will identify which type of self-advocacy strategy you'll need to use to get your needs met.

You may identify things you can do without support, but this step will help you determine if you need additional external support in the form of accommodations, skill development (i.e. being taught a skill), or both.

If no external support is needed, the process can end here. If support is needed, move to step 3.

3. Identify accommodations and/or skill supports you will be requesting from others.

This is where you will get specific and detailed about what you are requesting.

STAGE 2: PREPARING FOR ACTION

This is where you prepare the exact language you will be using when making your request.

This is also when you will create formal documentation to submit with your request if needed.

(Don’t worry, I have downloadable request forms to help you if you need to submit a formal request)

Many requests will not require formal documentation, but this step will be important regardless.

STAGE 3: ACTION – REQUESTING SUPPORT

1. Inform...

Inform the person or party of your disability.

2. Educate...

Educate them on how this creates challenges for you in the context relevant to them.

3. Request...

Request the support and/or accommodations you need from them.

4. Collaborate and Solve...

If the supports and/or accommodations cannot be fulfilled as requested and require adjustment, work together with the other person or party to find a mutually workable solution.

Note that the preparation stages are significantly more intensive than the action stage and where a lot of the most important work of this process will happen. You will see that reflected in the amount of detail I put into the preparation portion of this post.

Ok, now that you have a view of the full framework, I'll walk you through each step and explain exactly what you need to do to complete it.

Please note that I cannot get into every nuanced detail of the framework in a social media post, so it may still feel like pieces aren't fully fleshed out by the time I'm done.

But I will do my best to provide as much information as possible so you understand the steps well enough to apply them.

Ok, that was the "whole," (context)... now let's move on to the "parts" (details) 😳

Framework details...

STAGE 1: PREPARATION – BEFORE REQUESTING SUPPORT

Step 1: Identify your underlying unmet needs

Identify the underlying unmet needs that are impeding your ability to function in the situation and setting where your challenges are showing up.

Zoom in on your challenge areas and identify what about your environment is mismatched with your needs and causing your challenges.

An important note about this step

This step is a mental / brainstorming activity and is one of the most crucial steps in the whole process... it's also the step that requires as much internal experience input as possible. The more, the better.

Skipping this step and then asking for support would be like asking a doctor for help without telling them what's bothering you.

Parents and Caregivers

This is where advocacy on behalf of someone else becomes particularly challenging and why including them in the advocacy process (i.e. giving them opportunities to self-advocate) is so crucial.

Incorporating the autistic person in this part of the process will increase the likelihood that you will uncover the true needs that are going unmet and not mistake *responses* to unmet needs for the needs themselves.

Demand avoidance is a good example of this as it is often a sign that there is an underlying unmet need that has not yet been identified. But is also often seen as the need itself.

So the solutioning therefore often orients around reducing and removing demands rather than looking for unmet needs that are causing the autistic nervous system to respond protectively (with avoidance).

Back to step 1, identifying underlying unmet needs...

To brainstorm what your unmet needs might be, you will want to figure out what the actual cause of your challenges are.

Specifically, what the mismatch between your autistic brain wiring and environment is that's creating those challenges. (This mismatch is the unmet need you will be looking to address.)

When it comes to uncovering autistic unmet needs specifically, there are three main autism-related challenge areas you'll be thinking about...

1. Sensory
2. Social
3. Cognitive (learning/processing)

Note:

If your challenges are not related to any of these categories, they are likely not occurring because of your autism and may be due to different co-occurring neurological conditions.

They may also be due to a "regular" human need like hunger, exhaustion, being sick with an illness that isn't chronic, like a cold or the flu, etc.

If your unmet needs are not directly related to your autism, you can still proceed with the remaining steps, but the specific frameworks I cover in step 2 (RMATT/EASE) may not directly apply as cleanly as they do for autistic challenges.

Step 2: Identify the correct self-advocacy support strategy

Now, as I said, autistic support needs fall into three main challenge areas...

- Sensory
- Social
- Cognitive

But within each area, there are two main support pathways...

- Accommodations – adjustments to the environment

- Skill development support – adjustments to what the autistic person knows how to do... in other words, being taught an underdeveloped skill

Skill development support is much harder to obtain, but it's still an important part of the solutioning process because if it turns out to be a realistic option, it needs to be considered at this stage in order to be identified as a potential solution.

Now, to determine which type of support you need, I created a decision tree with two support frameworks built into it.

This is where the hand-holding I promised becomes particularly visible. 😊

DECISION TREE FOR IDENTIFYING SUPPORT

1. Start by asking if your challenges are sensory related.

IF YES...

Use the RMATT framework (details to come) to identify which sensory support strategy is best for the specific scenario you are in.

The RMATT framework will help you determine if accommodations are needed, or if skill support is needed (or both).

If accommodations are needed, you will brainstorm accommodation requests.

If skill support is needed...

You can use the EASE framework (details to come) to prepare for requesting skill support.

If your challenges are NOT sensory related...

2. Ask if they are social challenges.

IF YES...

Ask if the social challenges are due to an underdeveloped skill or something else.

If they are not skill related... you will brainstorm accommodation requests next.

If they are skill related and skill support is needed...

Use the EASE framework to prepare for requesting social skill support.

If your challenges are not social related...

3. Ask if they are cognitive challenges (learning challenges, processing challenges, etc)

IF YES...

Ask if it is skill related or something else.

If something else, brainstorm accommodation options next.

If skill related, use EASE.

USING THE RMATT FRAMEWORK

For sensory support, you will want to brainstorm which sensory support strategy is best for the situation you are in by working your way down the RMATT list.

1. Remove
2. Modify
3. Advocate
4. Temporarily Tolerate

1. The first option you'll want to consider is... REMOVE self or trigger.

Think, leaving an overstimulating environment or turning off loud music.

This is a self-accommodation. Meaning, there is no barrier for you to make this adjustment. If you can do it, you just do it.

2. The second option you'll want to consider is... MODIFY environment to minimize trigger.

Think, wearing noise canceling headphones, or having a fan on at night to help you sleep.

This is another example of a self-accommodation.

3. The third option you'll want to consider is... ADVOCATE for understanding and accommodations.

This is where external accommodations show up. These are remove and modify accommodations that you CANNOT do without external support.

Think, soundproofing a bedroom, asking to be seated in the aisle of an airplane or with extra legroom...

Or a good parenting example would be asking for your autistic child to be seated away from a window if the classroom is near a busy street.

This is where external support becomes necessary and advocacy becomes mandatory because changes cannot be made without external support.

And finally, the last option you'll want to consider is... TEMPORARILY TOLERATE. This option should only be considered last when factors are fixed and all other options are not accessible.

The approach here is focusing on physical and mental regulation strategies that help an autistic person temporarily tolerate situations that are typically intolerable to them.

A DEEPER UNDERSTANDING OF THE TEMPORARILY TOLERATE OPTION

Temporary tolerance is often required/forced and not coupled with approaches that aid the nervous system through the experience.

With the correct supportive nervous system strategies (think, breathing exercises, meditation, mental count-downs) and other external supports, this can be taught as a skill and used as a healthy and regulating coping strategy when all other support options are unavailable.

Temporary tolerance is a skill that can be taught

STRATEGIC tolerance is a skill, REACTIVE tolerance is a protective nervous system response that focuses on survival and can have an extremely detrimental psychological effect on the autistic person.

The skill of temporary tolerance falls into the category of what is often described as positive mental health strategies...

But I call them "discernment-based therapeutic approaches," because they focus on a person discerning for themselves what is happening inside their own body and choosing the best approach for themselves in the moment.

Learning these strategies can meaningfully improve any autistic person's life, but ONLY if learning the skill is "self-aligned." Meaning, that the autistic person is CHOOSING to learn and apply it and is not being forced into it.

APPLYING THE RMATT DECISION PROCESS

At this point in the process, if you discover that you can apply the REMOVE and/or MODIFY strategies without external support, apply them and be done (😉 😉).

Think, changing your own clothes if they are triggering you... wearing noise canceling headphones... leaving a loud venue... etc.

But if external supports and/or accommodations are necessary... move to step 3 of the framework to prepare for requesting help.

Note: If self-accessible strategies are possible, it is best to try those before requesting external support. Having exhausted all self-accessible possibilities prior to seeking support will strengthen your case when you do get to that step.

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USING THE EASE FRAMEWORK

The EASE framework will help you prepare an intentional, structured, and organized request for skill development support.

Use this framework when skill support is needed. This can be for sensory skills (i.e. temporary tolerance as a learned skill), social skills, or cognitive skills.

EASE stands for...

1. Educate
2. Advocate
3. Solve
4. Employ

As part of your preparation for requesting skill support, you will prepare for steps 1 and 2 of EASE, starting with...

1. Educate – This part of the framework will be directed by you. When requesting skill support, you will first need to educate the other person/party on what your challenges are and why.

2. Advocate – This part will also be directed by you. This is an extension of step 1. First, you explained your challenges, now you will explain your *needs.*

The next two steps outline what should come next in the process after you have formally requested skill support.

Steps 3 and 4 are included as context for steps 1 and 2 so you can see the bigger picture as you prepare for your request. (This framework is structured whole-to-part, to help you keep the big picture in mind as you work through the preparation process.)

3. Solve – This step should be a joint conversation, not exclusively directed by you.

During this step, you will work with the other person/party to come up with a structured skill development support approach that you both believe will meet your support needs.

4. Employ - This step should be entirely directed by them. During this step, they are providing support and you are engaging as a participant.

When you get to Stage 3, actually requesting the support (which we will get to in a bit), you only need to come prepared to direct the first two steps.

Step 3 of the preparation stage (what we are about to move to) will walk you through how to do that preparation.

Now that you have identified whether you need accommodations, skill support, or both, you can move to step 3 of stage 1.

STAGE 1: STEP 3: Identify specific support/accommodations to request

This is a brainstorm activity. PERFECTION IS NOT REQUIRED.

You do not need to come up with a perfect solution or predict whether or not your request is actually feasible for the other person/party or institution to fulfill...

You just need to come up with something that seems reasonable. This will become your starting point if you are told there are limitations preventing them from fulfilling your request.

Be specific.

Be as specific as possible with your request. Make them bounded (not open-ended) whenever possible.

This step should not be skipped. This is arguably the most important step to increase the likelihood that the support you get will be effective.

FOR ACCOMMODATION REQUESTS

If you have determined that accommodations are required (sensory, social, or cognitive) brainstorm specific accommodations that you feel should be feasible and are likely to get your needs met.

Be specific. Be explicit. Think about logistics and feasibility.

Write everything down.

FOR SKILL SUPPORT REQUESTS

If you determine that you need help developing a skill (or you are a parent figuring this out for your child)...

Brainstorm what the needed skill might be.

- Use Google. See what's out there when it comes to information about the skill you need help with.

- Think about what the person/institution might feasibly be able to help you with.

- Think about if and how the person/institution can logistically offer you that support.

Write everything down.

- The more you have on paper, the easier it will be to communicate your request when you are ready to make it.

Perfection is NOT required.

- Do all of this to the best of your ability. If you go in with something, even if it's not feasible, it will be better than going in with nothing. As I mentioned earlier, this will give you a place to start if you have to find a mutually workable solution together.

Next, think about WHY you need this skill support. What about your current situation requires the skill, and how is not having the skill affecting you in that situation?

Write down everything you can think of that would help another person understand why you have these specific challenges and why you are requesting this specific type of support.

This will become part of your request.

Finally, think about how your challenges are directly caused by your autism.

Write down any explanation you can think of that points to how the challenges are directly tied to autism.

Then, at the end, write this down...

"The challenges I just outlined are all directly related to my disability. I am formally requesting disability support for this challenge in the form of skill development support."

This language is not a guarantee that you will get what you are asking for, but it will directly connect your request to disability law (the Americans with Disabilities Act [ADA] in the US, and similar laws in other countries).

Now that you have all your support and accommodation requests worked out, you can move to the next stage... preparing your formal request documentation.

STAGE 2: PREPARING FOR ACTION

This stage takes all of the preparation work you did with the decision tree activity, RMATT, EASE, and all of the work you did figuring out how to articulate your disability and support needs most effectively, and helps you consolidate it into a concise request that you can share with others, either verbally, or in writing.

As I mentioned earlier, many requests will not require formal documentation, but some will...

Think... workplace accommodation requests, school/university accommodation requests, government or other institutional level accommodation requests.

But even when formal requests are not needed, this step is still extremely important because it gives you a structured way to organize, consolidate, and simplify your thoughts before making your request.

This will make your request, but more importantly, your needs... much easier for others to understand. Which will then make it significantly more likely that they will agree to provide the requested accommodation.

Think... asking for accommodations from family members, friends, neighbors, work colleagues... asking for accommodations related to extracurricular activities, entertainment venues, restaurants... etc.

Now, in certain situations, you'll need to submit a formal request for some accommodations and not others.

A good example of this is requesting airport and flight accommodations.

Certain airport and flight requests do require formal documentation, but many do not.

(Thank heavens. Imagine having to submit a form to request extra legroom because you get debilitating anxiety in restricted spaces... but also having executive dysfunction and having to wage war against your own brain just to fill out the form. 😅)

But even when you don't technically need formal documentation, having a clear articulation of what you need *before* asking for it will ensure the other person or party fully understands why you need it.

Here's a personal example to take us from abstract concept into real-life circumstances...

For the past 5 years, after discovering I could ask for flight accommodations for my disability, I have always called the Delta disability hotline to get help when booking a flight.

This is for getting seating help, but also to get help with the actual booking process, because my autism gives me MASSIVE anxiety about that as well.

Before having this process fully formalized in my own mind, I used to call the hotline for support without preparing specific language in advance. This meant that I was explaining what I needed slightly differently every time.

The problem with this was that one time, without realizing it, I used language that made the person I was talking to misunderstand my disability and accommodation request.

I had explained that I'm autistic and that I have anxiety when in restricted spaces... two things that should have been enough for the other person to understand the accommodation request was disability-related.

Except in this particular instance, with this particular person, the word "anxiety" definitely confused her.

The best explanation I can think of is that my wording made her think the anxiety was unrelated to my autism... and that she also had a misunderstanding about *anxiety*... thinking it's not a disability, which it very much is for many people.

This resulted in me not getting the accommodation I requested.

I was also on the verge of tears for most of that conversation and completely wracked with anxiety as I tried to make sense of her response and come up with a better way to explain myself. Which, ultimately, did not happen during that conversation.

Now that I have this process to work through ahead of those types of conversations, I can plan the exact language I want to use ahead of time to connect my request to my disability so there is no misunderstanding or confusion as to why I actually *need* the thing I'm asking for.

STAGE 3: ACTION – REQUESTING SUPPORT

1. Inform

Inform the person/party of your disability.

In many cases it may not be necessary to disclose your actual diagnosis. This will depend on the context of the situation you are in.

2. Educate

This is where all of your preparation turns to action and where your self-advocacy becomes most impactful...

Particularly when it comes to sharing how *your* disability manifests for *you,* specifically.

This is crucial because no two people with the same diagnosis will share the exact same combination of challenges and needs.

You'll want to describe how the disability affects YOU, specifically.

During this step, you will provide information that explains why your disability is hindering you in that particular environment and creating the specific challenges you are experiencing.

3. Request

This is when you explicitly request the support and/or accommodations you previously identified.

If submitting a formal request is not required, you can still share your request in a written format.

This is a particularly helpful approach for many autistic people who struggle to articulate their (often highly complex and intertwined thoughts) on the spot. The written format can be used

as a self-accessible accommodation to supplement what you are explaining verbally regarding your request.

You can also just verbally explain your needs if preparing a written request is not feasible for you. This can be a challenge (i.e. barrier) for people who struggle with executive dysfunction.

With your request, do your best to explain why the support and/or accommodations will help you.

If the person/party brings up logistical limitations, that's when you will move to the final step in the self-advocacy framework...

4. Collaborate and Solve

Note that this step in the "action" stage of the self-advocacy framework maps to the "Solve" step in EASE (a preparation framework). The two frameworks have connection points, but are not interchangeable.

During this step you will work with the other person/party to find a solution that is mutually workable.

This will be a brainstorming conversation and will require both parties to be invested in a mutually positive outcome.

Which brings me to my next point that should be considered carefully at the start of this entire process...

No matter how much preparation you do, requesting support will NOT be effective if you are dealing with a hostile person/party or environment (think unsupportive/hostile family members, toxic workplaces/bosses, unsupportive schools/teachers, unsupportive religious environments, etc.).

In fact, in those instances, disclosing your disability could backfire and result in even worse treatment and discrimination than you were experiencing before.

Be very careful when deciding who to engage with in this way. If the other person/party is supportive, agreeable, and actually wants to help you (even if it's because they are legally obligated to) there is a much higher chance the outcomes will be positive.