

The SMART Approach

A Handbook for Parents of Children with Autism

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Introduction

The autism spectrum.

Not too long ago, I wasn't sure what those words meant. Maybe I still don't. But it's no longer something that happens to other families.

Now it's happening to mine and I'm at a complete loss.

I look back on those early days, cuddling her against my chest so she could hear my heartbeat, the warmth of her body and that intoxicating new baby smell filling my head with sweet dreams for her future.

The details were fuzzy, of course, but some things were as clear as her little button nose.

She would fill our home with the pitter-patter of little feet and bursts of laughter. The refrigerator would be a messy collage of colorful preschool paintings, alphabet magnets, and stickers of accomplishment.

As she got older, she'd bring friends home for pizza and pajama parties and they'd stay up all night sharing intimate secrets not fit for parents' ears. She'd excel in any path she chose and grow up to be happy and successful. In my fantasy, there was no limit to her potential.

I'm not sure when I first noticed that something about her was, well, a bit unexpected. I wondered what to make of it, or if it was something that should be ignored. Better left unsaid, I thought at first.

She's uniquely her, and I wouldn't want her any other way.

Eventually, others started to notice, too, and I realized that some of her behaviors could no longer be ignored. Not if I wanted what's best for her.

My concerns grew as she did and I needed answers. Not that answers were easy to come by, but come they did. By the time we finally heard the words, we'd really been through the ringer.

The autism spectrum.

You wouldn't think so, but all I felt was tremendous relief. All my anxiety about what could potentially be wrong fell away and my tight muscles relaxed for the first time in months. A diagnosis at last.

You can't help your child if you don't know what's wrong.

If she had a broken arm, we'd put it in a cast. If she were nearsighted, we'd get her some glasses. You can work through those things pretty quickly and do what needs to be done in the best interests of your child.

The autism spectrum isn't like that, though, is it? Actually, it's nothing at all like that, and I don't know what I'm supposed to do or how I'm supposed to feel about it.

Relief has given way to a mixture of angst and abject fear of the unknown. Where do we go from here? What do I need to do to give her the future she deserves? There's so much to learn that now I'm even more overwhelmed than I was before the diagnosis.

I wonder if that future I took for granted is entirely out of reach for my child. Maybe no one can say at this point.

It's not that I lack for advice. Friends, family, and even total strangers have something to say, though much of it is contradictory. What I need is an expert.

Where can I turn? Who will help us through this? Our pediatrician? A neurologist? The school or therapists or behavior analysts? What do those people do, anyway?

I have so much to learn. What, exactly, is the autism spectrum? Why did this happen to us? What can I do to prepare this beautiful child for a full and happy life? I don't mind telling you that I'm feeling a little lost.

Where do I go from here?

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Have you been asking yourself the same questions?

Now that you've learned that your child is on the autism spectrum, you too might feel overwhelmed or terrified. You might even wonder if you're up to the task; then you're wracked with guilt over having those thoughts.

These feelings are all perfectly natural. If you've let guilt about all this creep into your life, let it creep right on out.

You want the best for your child, as most parents do; you're just not sure how to make that happen.

That's where we come in.

We'll walk you through those first steps. We'll help you get organized and set the foundation to prepare you to take on this awesome task of raising a child who happens to be on the spectrum.

The first thing on your "to do" list is to take a deep breath and cut yourself some slack. Now let's start the journey together.

# Simplify

After receiving the diagnosis of Autism Spectrum Disorder (ASD), your mind must be racing with questions and concerns. That's certainly understandable. After all, you want to be the best parent you can be. You want to provide your child with everything possible for a fulfilling life, and that's as it should be.

No child comes with a handbook and your child isn't any different in that respect. Like parents the world over, you will most assuredly make some mistakes. Actually, you can count on it. But chances are that you'll be OK, and so will your child.

The keyword is "simplify."

Simplify your thoughts, your home, and your schedule.

Simplification will help you be better organized and ready to take on this of raising a child diagnosed with autism.

### **Thoughts**

Thinking too far into the future can leave you feeling tense and overwhelmed.

Take a deep breath and get your pen and paper or keyboard ready. Now, concentrate on the present. What can you do – right in this moment – to improve your child's life? Come up with an action plan.

- 1. State the problem.
- 2. List potential solutions.
- 3. Take action.

Initially the problem may be finding the right therapies. You may need to do some additional research to find potential solutions. These may include intensive behavioral services, speech therapy, occupational therapy, or a combination of therapies. From there, you can take action by educating yourself on each solution and weighing the potential benefits.

The internet might seem like a great place to find answers, but that's not always the case. When searching online, make sure you're using qualified, reputable sources.

You might find talking with other parents who have some experience raising a child on the spectrum to be helpful in a different way. Just keep in mind that one child on the spectrum is one child on the spectrum – what works for one child may not work for yours.

#### Home

Minimize distractions and make your home easier to navigate. These days, it's far too easy to get caught up in buying all of the latest toys and gadgets, especially for our kids. Do your best to get rid of clutter, because it can over-stimulate your child and negatively affect everyone in the family.

Keeping a clutter-free home can prevent problem behaviors from occurring simply by removing the potential for these behaviors. There are two reasons for this.

First, when there are fewer objects around, there are fewer objects to be thrown or broken when your child is having a difficult time.

Second, overstimulation from the outside environment can contribute to problematic behaviors.

The most important spaces are your child's room and shared living spaces, such as the living room, kitchen, or family room.

Make these rooms work for you and your family. Keep what you use frequently and get rid of unnecessary objects and furniture. Your discards don't have to be wasted. You can sell them, donate them to charitable organizations, or gift them to friends and family. This exercise can turn into a feel-good experience.

Now that you're left with the "keepers," take a look around. If it still feels too cramped or cluttered, consider rotating toys and such.

Store the extras in a bin in the closet or basement. Every month or so, rotate these items with those that were left behind. The rotation will refresh toys and other items, making them more interesting to your child.

#### Schedule

Create a schedule and stick to it!

Schedules organize and simplify our lives when used properly. When you get overwhelmed, you can glance at your schedule for one day or even the next few hours and focus on those tasks without worrying about next week and beyond. Be sure to schedule time to care for yourself, running errands, children's events, and meetings.

Certain activities should be scheduled at the same time each day.

This includes such things as morning routines, meals, and bedtime

routines. Performing these activities at the same time each day helps to create a stable environment.

Consistency will help your child maintain a routine and know what they can expect. Most children thrive in a predictable environment. For some, it's quite a relief to be able to anticipate what might happen next.

There are many options for maintaining a schedule these days.

Smart phones, tablets, and laptops have an abundance of schedulekeeping features and reminders that are easy to update and reference.

If electronics aren't for you, a good old-fashioned calendar will do just as nicely.

### **Simplify Worksheet**

First, simplify your home. Go through different rooms of your home and sort items to be thrown away, donated, or kept.

### **Shared space**

- ➤ Is there walking room to get around furniture or do you need to step over objects?
- > Does the furniture need to be rearranged?
- Do you have an organization system for objects?

#### Kitchen

- ➤ Is there adequate space to walk around?
- ➤ Are cooking utensils and knives stored in a safe location?
- > Are the counters cleared?
- ➤ Do you have an appropriate organization system for all your kitchen essentials and food?

#### **Bedroom**

Your child's bedroom should be a safe and comfortable space for them.

- > Does furniture need to be rearranged and is it the right furniture?
- > Do they have some preferred activities available in their room?
- ➤ Are you able to navigate the room without stepping over objects?

## **M**otivate

Motivation is key in so many areas of our lives. We simply cannot expect our child diagnosed on the spectrum to complete any work if we're not able to motivate them. This can be quite the task!

Each child will find motivation in different things. We sometimes make the mistake of thinking just because a child enjoys a certain activity or toy, that they will work for that activity or toy. This is not always the case. However, preferred activities and toys are good indicators that your child may work for those. Interests change over time, as well as satiation and deprivation.

Satiation occurs when the child has had more than enough time with that one activity or toy.

Deprivation is when the child has had too little of the activity or toy. When deprivation occurs, these activities and toys will act as a strong motivator, and there's a greater chance your child will complete demands. In addition, your child may be more willing to complete harder demands or more demands than usual.

Furthermore, what your child may work for one day may not be what they are willing to work for the next day. That's why it's important to rotate motivators for your child even if they have not expressed satiation. Ideally, you want to have a variety of motivators for your child. This helps to prevent you from being in a difficult situation when your child loses interest in one activity or toy.

Take some time to fill out the worksheet at the end of this section to determine what may motivate your child. Reevaluate the motivators

you use on a regular basis. This will help you in your quest to provide proper motivation for your child.

### **Delivery**

To use these motivators to your advantage you must structure how they are presented to your child. You want to reward your child for following directions or completing demands. Therefore, do not deliver motivators until after the child has completed the task you instructed them to do.

As an example, if you would like your child to brush their teeth, don't deliver the motivator *while* they're brushing their teeth or *while* they're walking to the sink to brush their teeth. Wait until they have finished brushing their teeth.

#### Other factors

Motivation can be effected by several things, so don't get discouraged if you're not able to motivate your child with activities or toys.

Has your child had enough sleep? Too much sleep? Is your child ill with the flu, infection, headache, etc.? Are they hungry? Thirsty? Hurt? Has there been a change in medications? These may seem like events you would notice right away, but if your child is not able to communicate effectively, these things may be harder to detect.

Also, keep in mind the difficulty of the demands you place on your child. If you want your child to brush their teeth independently, but they haven't independently held a toothbrush, start with rewarding the

smaller demand of holding a toothbrush. Depending on your child's abilities, you may need to break down activities into smaller tasks. Once they are able to complete these smaller tasks, you can build on that and require more of them.

Also, keep in mind your motivation. Seeing your child succeed, and being a part of that, will motivate you!

### **Motivation Worksheet**

Use this worksheet to track what motivates your child to complete demands. List your child's interests in the areas of

| Toys                           |                          |                                     |
|--------------------------------|--------------------------|-------------------------------------|
| Music                          |                          |                                     |
| TV/video                       |                          |                                     |
| Games                          |                          |                                     |
| Books                          |                          |                                     |
| Activities                     |                          |                                     |
| Write other ways<br>or praise. | s you can motivate you   | r child, such as, high fives, hugs, |
|                                |                          |                                     |
|                                | tivators and their effec | tiveness.                           |
| Date/time:                     | Motivator:               | Was it successful:                  |
| Date/time:                     | Motivator:               | Was it successful:                  |
| Date/time:                     | Motivator:               | Was it successful:                  |
| Date/time:                     | Motivator:               | Was it successful:                  |
| Date/time:                     | Motivator:               | Was it successful:                  |
| Date/time                      | Motivatore               | Was it successful:                  |

## Ask

You don't have all the answers, nor are you expected to. Ask questions when you have them, as minimal as they may appear. No question is unimportant.

You can seek answers directly from professionals in the field or through other parents, depending on your question.

There's a good chance that on occasion, you're going to get answers you don't like. That is OK. You can seek a second opinion and come to your own conclusion.

Don't wear yourself out looking for the answer you want. If you seek multiple opinions and the responses are not ideal, maybe take a step back and ask a different question.

Sometimes we need to accept the answers we get and move forward in a productive manner for our child.

Also, circumstances change, new research is published regularly, and your child is growing. As time progresses the answers you previously received may no longer be relevant.

#### **Professionals**

When seeking answers from professionals, it pays to prepare in advance. That's because parents often find themselves overwhelmed in the presence of professionals. It's not unusual to ask one question and receive an answer, and then become so fixated on the answer, you forget your other questions. Nor is it unusual to get distracted by the environment or new thoughts that pop into your head.

Prepare for these meetings by writing out your questions. This will help you stay organized and ensure that all your questions are addressed.

Once you get home, it can also be difficult to recall exactly what was said. That's why it's a good idea to take notes during these meetings. Later, you can look back at their answers and develop new questions for follow-up meetings. These days, you might even be able to contact the professional by email and receive written response.

#### **Parents**

You may ask other parents about their experiences. You can join web forums, support groups, or speak with parents you meet from your child's class or therapies. Hearing about their experiences will help normalize your experiences as well as provide you with some guidance.

If you don't have a specific question, that is OK too. You can simply ask for help. First, identify what you need help with. Maybe you need another parent to help you sort your questions for the professionals, or maybe you need help finding time for yourself. In any case, people are going to ask you questions and for help and you can do the same.

As you grow as a parent with a child diagnosed on the spectrum, you may find other parents seek out your advice. Again, keep in mind that what works for one child does not always work for another. Give your advice, but always encourage parents to seek further answers from professionals when the subject warrants this.

#### Other considerations

When you are out and about in public, someone may notice your child has different abilities and want to ask you about this.

Be prepared to answer questions on occasion. It's better for people to ask than assume. Use it as an opportunity to break stereotypes. If your child is able to answer the question that was presented to you, maybe you could encourage this individual to ask your child directly.

Finally, your child may have some answers for you. Depending on your child's ability to communicate, you can ask questions of them. If you don't know how to help your child, ask them! They may have insights they can share with you. If you're not sure if you have the proper therapy for your child, talk it over with them. What do they enjoy about therapy? What don't they enjoy? How can it be better? What are their goals?

Of course, we can't always accommodate our child's wants, but knowing what those wants are can help us determine what we need to do. Your conversations may be adapted or shorter, but it is important to include your child as much as you can. It's a team effort.

## **Ask Worksheet**

| Develop a plan before going into meetings with professionals. Use this outline to prepare yourself. | 5 |  |  |  |
|-----------------------------------------------------------------------------------------------------|---|--|--|--|
| Goal of the meeting:                                                                                |   |  |  |  |
| Questions you have before the meeting:                                                              |   |  |  |  |
|                                                                                                     |   |  |  |  |
|                                                                                                     |   |  |  |  |
|                                                                                                     |   |  |  |  |
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|                                                                                                     |   |  |  |  |
| Notes:                                                                                              |   |  |  |  |
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| Questions from the mee | ting content: |      |  |
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## Relax

You may think that relaxing is off the table, but it's not. You're a parent of a child diagnosed as being on the spectrum, so there's no doubt life will be challenging at times. That's why finding time to relax is important for you, your child, and the whole family. Sure, finding balance is going to be a task, but it's crucial that you put the effort into quality relaxation time from the start.

Parents sometimes report feeling selfish when they take a little time for an activity of their choosing. This is not a selfish act; this is a necessary activity that will make you a more effective parent. To be the best parent you can be you need to take care of yourself – and you deserve it.

### Identify

Identify the activities you personally find relaxing. Next, identify the activities each additional family member finds most relaxing. Every one of you should have a daily as well as a weekly or monthly activity to participate in to maintain balance in your life.

As little as five minutes a day to focus on yourself can make a meaningful difference. You may choose to do your relaxing alone with no distractions, or you may choose to include other members of the family. Quality relaxation may look different for each person, so don't worry about what works for someone else – find what works for you.

It's crucial that you commit time to yourself and hold yourself accountable to getting that time. Write your expectations down. This

simple exercise can make you more accountable and more likely to maintain those expectations. Complete the exercise at the end of this chapter and share your expectations with your family. You can support your family in getting the relaxation they need and they can do the same for you.

#### Make the time

Determine how much time each family member needs to get the most out of their relaxation. Block that time off and hold yourself accountable to complete your chosen activity during that time. If you start to stray from your scheduled time for consecutive days, then reassess your relaxation goals and problem-solve to get back on track.

You may need to make arrangements to ensure that you're able to have your time to relax. If alone time is what you want, ask your significant other, a family member, or friend to watch the kids during that time. If you have a significant other, take turns watching the children Otherwise, try to block off some time while the rest of the house is asleep.

You may find some daily "me time" is ideal or you may find completing an activity with your loved ones more meaningful. Some days you may want to be alone with your favorite book for 20 minutes, while other days you may find more joy reading a book with the family.

Neither choice is wrong.

## **Relax Worksheet**

| Each family member can complete their own exercise. Then get together      |
|----------------------------------------------------------------------------|
| and share what you have committed to, so you can support each other        |
| along the way. List activities you may do on a daily basis to relax. These |
| activities may last for five minutes to an hour at a time.                 |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
| List activities you may do on a weekly or monthly basis to relax. These    |
| activities may take over an hour to complete.                              |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |
|                                                                            |

| Determine your relaxation time and stick to it.                                     |                 |
|-------------------------------------------------------------------------------------|-----------------|
| Daily activity: Time of day:                                                        |                 |
| Weekly/monthly activity:                                                            |                 |
| Schedule a time:                                                                    |                 |
| Do arrangements need to be made to ensure your relaxati                             | on time? If so, |
|                                                                                     |                 |
|                                                                                     | <del></del>     |
|                                                                                     |                 |
|                                                                                     |                 |
| Feel like you're in a rut? List activities you think you may but haven't tried yet. | find relaxing,  |
|                                                                                     |                 |
|                                                                                     |                 |
|                                                                                     |                 |
|                                                                                     |                 |
|                                                                                     |                 |

#### **Ideas for Relaxation Activities**

### **Daily**

The following activities may be structured to last anywhere from five minutes to an hour.

- Reading (read something for pleasure)
- Music (play an instrument, sing, dance, listen)
- > Art
- Exercise (walk, lift weights, run, take a class)
- ➤ Meditate/pray/practice faith
- > Knit
- ➤ Play a game
- Writing/journaling
- ➤ Go to a coffee shop

### Weekly or monthly

The following activities may be structured to last anywhere from one hour to up to half a day.

- ➤ Take a class or seminar (cooking, art, gardening, etc.)
- > Escape room
- ➤ Go for a hike
- Attend a movie or play
- Attend a comedy show
- > Attend a sporting event
- ➤ Indoor or outdoor skydiving

- > Try a new restaurant
- > Get together with friends

## Take an Interest

Being a parent is a long and winding journey for anyone. Being a parent to a child diagnosed on the spectrum is certainly going to be a unique and individualized journey! You will find joy in your child and these times should be cherished. There are memories in the making.

Now is the time to take an interest in your child's preferred activities. Now is the time to show interest in the community and in helping to further awareness and acceptance.

#### Your child

Sometimes the best and simplest way to create these positive memories is to take an interest in what your child is doing. Yes, you're going to have to be a parent and set boundaries, schedules, and rules, but sometimes it's appropriate to take a step back.

Look for moments when you can join your child in an activity for no particular reason. That means not seeking out "age appropriate" activities with which to teach your child. It means allowing them to have a little time to simply enjoy what they enjoy – even if it doesn't seem age-appropriate or appears a little strange.

If your child likes to talk about appliances, take an interest in appliances. Not all the time, of course. Appliances cannot dominate all their conversation. On the other hand, why not let them discuss appliances for 10 minutes at time with Mom or Dad? You may not have a strong interest in this topic, but that's OK because your child does.

Listen to what they say, ask relevant questions, and research

answers on this topic with them. This is excellent bonding time for you, as well as a good exercise in listening skills.

If your child isn't especially interested in conversation, but has a keen interest in playing with cars, then play with cars with them.

Again, it may not be appropriate for them to play with toy cars, but inside of their own home and for small periods of time it's perfectly acceptable. You may find that over time, you're building a strong bond with your child over this activity. Then your child may be more likely to expand on this activity. Eventually, perhaps you can move from playing with toy cars to walking around showrooms and learning about cars more in depth. You never know where a seemingly unimportant activity can lead!

When you take an interest in your child's interests, as different as they may seem, your child may be more willing to take an interest in you and your preferred activities. It's one way of leading by example.

#### Outside of the home

You may find it beneficial to take an interest in community events and activities. Get involved at your child's school or extracurricular activities. In your local community, there is a subset community of families affected by autism. Take an interest in what they are doing. Are there local events, fundraisers, educational seminars, or other outreach?

Being involved in these activities outside of your home may make you feel less isolated. You don't have to be alone in this. Also, this can be a great way to increase awareness and acceptance in your local community. By being active and taking an interest in the cause you're

not only improving your child's quality of life, but that of your family, your community – and your own.

## **Treatment Worksheet**

| Record your goals as a parent. What outcomes would you like to see in |
|-----------------------------------------------------------------------|
| your child's treatment within the coming year?                        |
|                                                                       |
|                                                                       |
|                                                                       |
| Who does your treatment team consist of? Keeping a list of these      |
| professionals in one place can help you stay organized.               |
| Name:                                                                 |
| Profession:                                                           |
| Company:                                                              |
| Phone Number:                                                         |
| Email:                                                                |
| ~                                                                     |
| Name:                                                                 |
| Profession:                                                           |
| Company:                                                              |
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| Phone Number: |
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| Name:         |
| Profession:   |
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This handbook is a starting point for your journey. While the task of raising a child on the spectrum may seem daunting, return to the basics and the **SMART** approach.

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