

The Autism Mom Toolkit



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You just got a diagnosis. You're overwhelmed. You have more information flying at you than airplanes in the New York airspace.

Don't worry. You have time to read all the articles and books, and you will. But, practically speaking, what tools do you need now? Take a deep breath. We've got you covered.

1. Shared Google Calendar

If you're married (or have a partner or co-parent), and if you and your partner function as a team, this tool is invaluable. A new special needs parent will have potentially dozens of phone calls and appointments to schedule, and you'll need instant access to your partner's availability. Otherwise, the person doing the scheduling will either end up at appointments alone or making return phone calls for rescheduling. Both waste time and energy. Frustrating!

The shared Google calendar was especially important in the beginning of our autism journey, but we use our calendar as much now as we did when Henry's schedule was full of therapy appointments. We input everything, from Keith's varying work schedule to Henry's playdates to my Ladies' Night Out. Without it, my stress level would be much higher, and when Mom is stressed... everyone is stressed.

Need help? [Find directions for linking your Google calendars here.](#)

2. iPad

We could talk about the many problems with young children owning tablets, and maybe we will one day, but these are the ways it has positively affected our family.

***Use it to create visual schedules on the fly.**

Around the same time we were learning the value of pictures for the autistic brain, we were also struggling with bedtime. Keith created a simple visual schedule on the iPad with four pictures of Henry's bathtub, toothbrush, books, and bed. That evening Keith showed Henry the pictures and firmly declared, "Bath. Brush. Books. Bed." Bam. Henry was going up the stairs without complaint. We stared at each other. Could it really be that easy? Yes, it was.

***Find need-specific apps.**

In the last few years, the app-world has exploded with resources for children with communication needs. In one small container we have almost everything we need to communicate with our children and for our children to communicate with us. The value of this technology can't be overstated. A simple google search will reveal story upon story if you want to learn more. [Here's one of my favorites from 60 Minutes in 2012.](#)

Henry's conversational speech was very limited as a toddler. After showing him Keith's iPad just for fun, we were astonished to see what Henry could do. His fingers flew through spelling games, Memory games ... the very same activities he ignored unplugged. As he sped through the levels, we simply gaped. There was no turning back. Matching games, animals sound games, alphabet games, number games, drawing games, train-building games. You name it, he loved it.

***Finally, and most importantly for us, it's an aid for long waits.**

We mostly cook at home, but occasions sometimes call for meeting family and friends out for a meal. Taking Toddler Henry to a restaurant was nothing short of a nightmare. We endured stares and whispers that pierce my heart to this day. Never leaving the house was simply not an option for us, so it was after much debate and wringing of hands that we decided to bring an iPad with us to restaurants.

Life. Changing.

I didn't plan this. In fact, I planned the opposite. I bought the purse-sized coloring and activity books. I tucked the tiny toy figures into his diaper bag so he could act out stories. I was the typical mom, but I didn't have a typical toddler. Henry hated being forced to color. And play with little figures? Um, no, and it's certainly not what I wanted thrown in my eye when he became upset.

Today Henry is much more patient and tolerant, and restaurants aren't quite the challenge they once were. Still, the iPad continues to come in handy for us in other ways. (See #3.) Buying my 3-year-old his own, very expensive technology was never

part of my motherhood plan, and I bet it's not part of yours either. But we non-typical moms have to be flexible and adaptable, just like our kids.

3. The Go Bag

If you have a child, you need a Go Bag. If you have a special needs child, it's non-negotiable. What is it? A tote full of everything you need to "go" at a moment's notice!

The gift of the Go Bag is peace of mind. Having everything you need for an outing in one place will combat the hurry-scurry before leaving home and potentially prevent meltdowns and emotional distress later – both yours and your child's. If your child's needs include medical care, the bag could even save his life.

Our bag contains:

*** Headphones**

[Henry's headphones](#) aren't needed so much anymore, but for years he always requested them in the church sanctuary. The sound of singing en masse plus the organ was too much, even though he loves music.

*** Activity books**

Henry has never enjoyed coloring books or drawing, but he digs hidden pictures, puzzles, mad libs, and mazes. [Highlights](#) publishes wonderful series of activity magazines for all ages, including one we love called Puzzle Mania. Amazon and your local bookseller are also great resources for activity books like those from [Kumon](#) and [The Everything Kids' Mazes Book](#).

*** Regular books!**

Don't forget the obvious! Books are great for children of all ages.

* Snacks

Snacks are a given for a family like ours. Henry's dietary needs are, well, unique. Many of you can relate, whether your child has self-imposed dietary restrictions, food allergies, or other medical needs.

We like to use [Tupperware bottles](#) for water, but it's always nice to have a juice box stashed in your bag for impromptu trips or even an emergency. Don't do juice at your house? Toss in a water bottle or even [these milk boxes](#) that don't need refrigeration.

Obviously, the contents of your Go Bag will depend on your children's needs and will change over time. (Ours used to contain a [chewy train necklace](#), for instance.) Here are some ideas to get you started:

Diapers and wipes

Grocery bags (for trash)

Extra clothes

Medication

EpiPen

Small toys

Blanket/Lovey

Stress ball

[Hand fidgets](#)

Chewable fidget or [chewelry](#)

Bubbles

Notebook and pencils/pens

Drawing pad or coloring book and crayons

Books

[PECS](#) and/or visual schedule

Card games

Headphones
iPad or other tablet
iPod loaded with soothing music

4. The Binder

If your child has a diagnosis of any kind, you'll soon find yourself drowning in paperwork. The Binder is strictly for use by the caregiver, but I promise your children will reap the benefits.

What is it? IEP binder. Special Needs Binder. Care binder. What you call it isn't important; I just call ours The Binder. It started as a 1-inch binder and quickly grew to a 3-inch. Save yourself the trouble and start big. [Ours looks like this.](#)

What is in it? Ours contains every evaluation, IEP document, 504 document, checklist, and tip sheet I have collected over the years that is applicable to Henry's education. These are placed in chronological order. I use protector sheets to group like items. A set of IEP documents from one meeting, for instance, will be placed together in one protector sheet.

In the front of the binder are documents I may need to access quickly, like his Student Information Sheet. I also keep handy a list of Accommodations to Consider for Students with Problems in Organization, because I expect this could be needed as classwork becomes more difficult.. Another example would be the sensory input suggestions from Henry's former occupational therapist.

[Note: If your child has a medical diagnosis, you may want a separate binder for those appointments and related paperwork. This might include doctor's notes, lab reports, hospitalizations, food intake trackers, medications, growth charts, etc. See More Resources at the end of this post.]

When do I use it? Before an IEP meeting, I always reviewed the previous IEP goals as well as any testing that has occurred in the classroom since that meeting. Keith and

I then make a list of items we want to discuss with the team. I tag any relevant documents we will need in the meeting so they will be easy to find.

If you are hoping to add, remove, or revise a goal, I suggest bringing documents that would support your cause. In that case, you may want to keep pertinent teacher and/or therapist communication and samples of your child's classwork in your binder as well.

Why make it organized and pretty? I'm a firm believer that your appearance in an IEP meeting is as important as your documentation. You need to look like you have it together, even if you're falling apart in your car 5 minutes beforehand. The prepared parent shows the rest of the team that you take the time to research and understand your child's needs. Your requests are educated ones, not fueled by fact-less, emotional passion. And, let's face it, no one – including you – wants to waste the meeting time thumbing through haphazard files.

Why put your child's picture on the front? Easy. To keep your child's beautiful face in front of you at all times. If your binder doesn't have the clear-view front, pull one out and lay it on the table. You want to remember your child is a *whole* person with strengths and abilities, feelings and interests — and you want the rest of the team to remember that too.

The best advocate is the prepared advocate. We can't ask for what we don't know our kids need; we can't know their rights if we don't do our research; and we can't speak intelligently about any of this if we can't find the documentation.

Need help putting your binder together? Here are more resources:

- [Understood.org](#) has a helpful article and short video (2:20 minutes) on How to [Organize Your Child's IEP Binder](#).
- Pete Wright of [Wrightslaw](#), the leading authority on special education law, also has helpful advice on [Organizing Your Child's Special Education File](#).

- [The Thinking Person's Guide to Autism](#) has a [brilliant article by Jennifer Johnson](#) on how and why to use a care binder. Hers is more geared toward medical issues, but most of it still applies even if your child does not have a medical diagnosis. Her post includes a link for medical forms you might want to use, but that link has since been updated. [You can find them here.](#)

5. Can-Do Attitude

Our fifth and final tool in the Autism Mom Toolkit isn't tangible, but it's more important than all of the others. Without it, all the gadgets in the world will be useless to you. Caregivers must have a positive outlook.

Moms tend to be harder on themselves than anyone else ever could be. We criticize ourselves and second-guess our instincts. We read articles telling us what we're doing wrong and what we should be doing right. We ask our mothers and friends for advice on the most significant *and* the most trivial decisions. (Don't believe me? Scroll through any mother's Facebook feed.)

Yet, I would argue the worst mistake we can make in special needs parenting isn't one action.

The worst mistake we can make is believing our kids can't.

Can't feed herself.

Can't write his name.

Can't control her anger.

Can't overcome his fear.

Can't speak.

Can't communicate.

Can't learn.

Can't understand.

Can't graduate.

Can't work.

Can't.

If we assume our kids can't, we stifle their growth and strip them of their dignity. We also deny ourselves the greatest joy of autism parenting: the pleasure of watching a child accomplish what was once impossible. We never wish for our children to struggle, of course, but maybe that's what makes the joy so unspeakably awesome.

If I recalled all the ways Henry has defied expectations and myths, I would still be typing tomorrow. It's not only the visible accomplishments we recognize, such as acquisition of conversational speech; it's also the more subtle changes, like his insightful questions and noticing the emotions and motives of his peers.

Henry amazes us every day. And we are not alone. I've seen the great strides made in children we know from waiting rooms and joint therapy sessions. I've watched the documentaries and the television segments. I've read the memoirs. Here's what I've learned:

When in doubt, always assume competence.

A disclaimer: I do not support ableist thinking; I don't endorse harmful so-called treatments; and I am wary of anyone claiming a cure. What I encourage is a positive mindset that says, "My child can't do this... yet." Time and again, our children prove to us they are more capable than we can even imagine, if given the right tools and resources.

Was this helpful?

What do you think about the Autism Mom Toolkit? Did we leave out one of your must-haves? Did we inspire you to use Google calendar? Create your own Go Bag or Binder? We would love to hear your feedback! meredithdangel@gmail.com

