

A Week by Week Plan for the Next 100 Days

Getting Organized

The first thing you will need to do is get yourself organized. You may already find you've accumulated a lot of paperwork about your child and about autism in general. Organizing the information and records that you collect for your child is an important part of managing his or her care and progress. If you set up a simple system, things will be much easier over time. You may need to stop by an office supply store to pick up a binder, dividers, some spiral notebooks, loose leaf paper or legal pads and pens.

The Binders

Many parents find that binders are a great tool for keeping the mountain of paperwork down to a more manageable, size and for sharing information. You may want to organize by subject or by year. In either case, here are some of the subjects that you are likely to want to have at your fingertips:

Contacts

A section for service providers, caregivers and others

Schedules

A section for therapy times, program start and end dates, deadlines

Diagnosis

A section for medical documents and any prescriptions

Therapy

A section for speech, occupation therapy, SI and so on (multiple or sub sections may be necessary)

Individualized Family Service Plan (IFSP)

A section for your child's IFSP and related documents (for children under three years of age)

Individualized Education Plan (IEP)

A section for your child's IEP and related documents (for children age three and older)

We've included a sample contact list, phone log and weekly planner in this kit so you can copy and use them as needed. You may also want to summarize your child's progress in therapy and at school with cover sheets in each section; sample summary sheets are also in the Resources section.

Using Your Weekly Planner

The timeframe and action items will vary depending on your child's symptoms, age, where you live and what you have already accomplished. Even if you are very on top of this, it may take a while to be able to access additional evaluations and the services that your child needs.

Start Now

Week 1

Complete Evaluations

If your child has not had a complete work up, schedule the remainder of necessary evaluations (see Getting Services below).

Getting Services

If your child is younger than three, you'll start with Early Intervention (EI) often through your state department of health. If your child is three or older, you'll start with your local school district. Call to begin the process of getting services. EI or your school district may want to conduct evaluations of your child (at their expense). This can be a long and time consuming process, but may be useful in further determining the services that are needed.

Keep a Phone Log

Try to set aside some time each day to make the phone calls necessary to set up the evaluations and to start the process of getting services. There may be a waiting list for services and evaluations, so make the calls as soon as possible and follow up as needed. Don't hesitate to put your name on multiple lists so you can get the earliest appointment possible. Some of the professionals who provide services through Early Intervention or Special Education may take a specified number of days to complete evaluations or begin services.

Start a Video Record

Try a variety of settings and show a range of behavior. Note both good and not-so-good behavior so that, in the future, you will be able to recognize where your child was at that point in time. Make a new recording every three months at home, in therapy sessions, wherever. These video "snapshots" can be used to track your child's progress and help show what effect a particular therapy or intervention may have had. Label the tapes or discs with your child's name and the dates they were recorded.

Week 2

Getting Support

Find a support group or a parent mentor. If your child is in school, you may also want to find out if your district has a Special Education Parent Teacher Association (SEPTA), which may offer informational meetings and parent outreach.

Getting Services (Follow Up)

Follow up on services. Continue to check status on waiting lists and available programs.

Research Treatment Options

Start to read material, join online groups and ask questions that will help you understand the treatment options that are available and what might be right for your child and your family.

Week 3

Getting Services (Continue to Follow Up)

Follow up on services. Continue to check status on waiting lists and available programs. Keep using your phone log to record the dates you contacted service providers and track when you may need to make another call.

Play with Your Child

Play with your child. Play is an important part of any child's development and is a critical part of learning socialization for a child with autism. We've included a very helpful article, *Ideas for Purposeful Play*, from the University of Washington's Autism Center that illustrates how to include useful play activities, to help your child learn.

Set Aside Sibling Time

The siblings of children with autism are affected by the diagnosis as well. Consider spending time talking together about their feelings. Start a "Joy Museum" together of happy memories. Talking about these times can help them remember that their lives involve a lot more than autism.

Play with Your Child

Ideas for purposeful play are included at the end of this section of your tool kit.

Week 4

Build Your Team

By this time, your child's team of therapists, educators and caregivers is probably taking shape. Continue to look for service providers and observe as many therapy sessions as possible to identify new recruits for your child's team. Talk to other parents who may know of therapists with time available for your child. You don't have to wait until every member of the team is in place before beginning therapy.

Create a Safety Plan

You may already have had to adapt your home because of your child's behaviors or needs. You've probably already read the section of this kit called Create a Safety Plan. If not, carve out some time to survey your home for possible problems and begin contacting local safety personnel to plan ahead to ensure your child's safety.

Plan Some Time Away

Plan some time away from your child. You will do a better job helping your family if you take care of yourself. Even if it's just going for a walk alone, you are going to need a break so that you can come back with a clear head.

Week 5

Continue Building Your Team

See Week 4.

Review Your Insurance

Investigate your insurance coverage to see what, if any, therapies are covered and make sure that you are getting the most from your provider. Your health insurance may cover therapies or services not covered by your child's IFSP or IEP. You may need to create a separate binder to keep track of insurance claims. Document everything.

Get to Know Your Child's Legal Rights

Familiarize yourself with your child's rights. There is a wealth of information available. You may find out your child is entitled to services you weren't aware of or hadn't considered.

Do Something for You

You've made it through a month, and it may have been one of the most challenging months of your life. Remember to take care of yourself. Remember who you were before the diagnosis. Spend some time on an activity that you enjoy. You will find it helps you face the challenges ahead. There are probably friends and family in your life who would love to help, but may not know what you need. Don't be afraid to ask for help.

Week 6

Continue to Research Treatment Options

Continue to research treatment options. If possible, go to a workshop or look for additional information online.

Connect with Other Parents

Go to a support group or spend some time with a parent who can help you along your journey. You'll learn a lot and being around people who know what you are going through will help you stay strong.

Find Childcare

Get a babysitter. Look into qualified babysitting services and respite care. Don't wait until you're desperate—find someone you're comfortable with and plan a night out. If you already have a great babysitter, invite her or him to spend some time with you and your child so he or she can adjust to the new techniques your family is using at home.

Build Your Team

Continue to follow up on services and research any new possible providers.

Schedule a Team Meeting

If you've built a team of therapists, you may want to call a meeting to establish procedures and goals and open lines of communication. You'll also want to continue observing therapy sessions and using what you learn at home. If it's difficult to schedule a time for the service providers to meet in person, you may want to schedule a conference call instead.

Week 7

Become Competent in the Intervention Methods You Have Chosen for Your Child

Take advantage of parent training. Therapists often provide parent training that will help bring the methods used at therapy into your home and help your child's progress.

Create a Schedule

Having a written weekly schedule for your child's therapy will help you see if you've scheduled your time as well. It will also help you plan for the other members of your household.

Continue Learning about Treatments and Services

Consult the Autism Speaks Resource Guide for contacts in your area.

Spend Some Time Organizing Your Paperwork

Organize any paperwork that may have piled up. Try to eliminate any materials you won't need.

Week 8

Check Your Progress

Look back through this action item list. Is there anything you started that needs follow up?

Investigate Recreational Activities for Your Child

Add a recreational activity, such as gymnastics or swimming, to broaden your child's development.

Plan More Sibling Time

Your typically-developing children will no doubt be richer for having a sibling with autism. But maintaining as much normalcy as possible will help them reach their potential too.

Make Contact with Friends and Family

Stay connected. Make contact with your friends and family and participate in community events. Keeping up your social life will help you safeguard against feelings of isolation.

Spend Time Alone with Your Spouse

Plan a relaxing and fun activity with your partner. After all, you've just made it through month two.

Week 9

Round Out Your Team

Continue to evaluate service providers and therapists.

Use the Internet

Get e-savvy. Spend time researching online resources that will keep you up-to-date. Add useful websites to your favorites, register for e-newsletters and join list serves where parents and professionals share information.

Continue to Connect with Other Parents

Stay active with a support group or, if possible, socialize with other parents of children with autism. Being around other adults who understand what your family is going through will help you stay strong.

Check in on Your Child's Sessions

Continue to observe your child's therapy sessions. Your child should be getting used to his or her therapy routine at this point.

Play with Your Child

Play with your child. Continue to use the strategies you've learned from parent training sessions and other resources.

Week 10

Schedule a Team Meeting

It's team meeting time again. Schedule a meeting to discuss progress and strategies. Stay involved with your team by continuing to attend as many sessions as possible.

Rally the Troops

Encourage your team. Let them know you appreciate everything they are doing for your child.

Plan a Family Outing

Schedule an activity designed to include your child with autism and utilize strategies you've picked up from therapy. Ask your child's therapist to help you with specific strategies to make the outing a success.

Brush Up on the Law

Continue to learn about your child's legal rights.

Week 11

Check Your Child's Progress

Look for progress. Hopefully, your child has been through a consistent month of therapy at this point. Review your binder and videos to see if you notice improvements. Continue to attend sessions too. Take notes on what you see. Keep a copy in your binder and bring them to your next team meeting.

Dig Deeper into Treatment Options

Set aside time to do some research and reading on additional treatments and therapies. Make notes and copy useful information to include in your binder.

Week 13

Hold a Team Meeting

Check on progress again. You should continue to see progress after at least six weeks of consistent therapy. If there has been little or no progress, call another team meeting to brainstorm and make adjustments to your child's routine.

Continue Learning

Keep learning about autism. Books, seminars, movies, websites – all sorts of sources can help you deepen your understanding of autism and your child. See the Suggested Reading List in this kit for ideas.

Do Something for You

Enjoy some "me" time. Do something nice for yourself – you've made it through 100 days!

Week 12

Reconnect with Your Spouse

Take some one-on-one time to enjoy each other's company. If communication has been difficult, consider scheduling time with a counselor to keep your relationship healthy.

Continue Connecting with Other Parents

Keep going to support groups. Parents are amazing resources and will help provide emotional and practical support. Look into additional groups in your area if you don't feel like you've found the right one for you.

Sign Up for More Training

Using the methods you are learning from your child's therapists will help create a productive environment at home so your child will have the best chance of obtaining his or her goals.

Ideas for Purposeful Play

From the University of Washington Autism Center Parent Care book

Imitation: Object and Motor

- Sing finger play songs such as the Itsy Bitsy Spider, 5 Little Monkeys, Zoom down the Freeway
- Utilize musical instruments: “Let’s make music”, play Simon Says, have a musical parade, slow down, speed up, “Follow Me Song”
- Figurines: know on barn door, follow the leader to the schoolhouse
- Block play: make identical block structures
- Painting and drawing similar pictures, strokes, circles, lines, dot art
- Dramatic play: feeding babies, pouring tea, driving cars or trains on tracks, hammering nails, stirring

Receptive and Expressive Labeling

Embed labeling into activities such as:

- House (cup, spoon, plate, door)
- Grocery store (orange, apple, banana)
- Dolls (body parts, brush, clothing)
- Barn (animals, tractor)
- Art: Colors, scissors, glue, markers, big crayons, little crayons
- Books: pointing and labeling objects, letters, numbers, shapes, etc.
- Sensory Table: put different colors of animals, shapes, sizes, common objects
- Park/Playground: slide, swing, ball
- Play Dough: use different colored play dough, animal shaped cookie cutters

Receptive Instructions

- Songs: “Simon Says” clap hands, tap legs, etc.
- Clean up time: put in garbage, put on shelf
- During activities request items, “Give me ____”
- Ask child to get their coat/backpack on the way outside or at the end of the day

Matching

- Lotto matching game
- Puzzles with pictures underneath
- Picture to object matching can be done as activity during play (have the child match the picture of a cow while playing with the barn)

Requesting

- Utilize motivating items (i.e. bubbles, juice, trains) to address requesting/communication
- Swing: wait to push until child makes the request
- Door: wait to open until child makes a request
- Lunch/Snack withhold until child makes request
- Art: child can request glitter, glue, stickers, paint, etc.