

EARLY AUTISM INTERVENTION & PROVIDER FIT WORKBOOK

An Advocacy Workbook for Parents and Caregivers of Young Children with Autism Spectrum Disorder (ASD)



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A guide from the On-Time Autism Intervention (OTAI) Program

The guidebook will give you information from research on effective intervention for young children with ASD and their families, intervention agency policies and practices, child learning, and behavioral characteristics, and family priorities and resources.

The workbook will lead you through questions that many parents face when their child is diagnosed at a young age with ASD. For example, many recommendations may have been suggested and you are trying to decide which ones your child needs. There are two main goals of this workbook:

1. To help you consider the options for your child using recommendations based on research on best practices for young children with ASD and child development
2. To help you consider the options for your child based on their unique characteristics and the specific needs of your family



WELCOME!

This workbook is meant to help guide and support parents and caregivers of young children with autism spectrum disorder (ASD). We will use the term ‘parents’ throughout this book to refer to any parent, caregiver, legal guardian, or foster parent who may be using this guide to make decisions about therapy for their child. We recognize and celebrate that all families are unique and different. Our choice of words is meant to keep our language simple and straightforward for those using this workbook.

There is no ‘one size fits all’ therapy for young children with ASD. Similarly, there is not one set of services or supports that will be useful or desirable for all families. Just as there is no *right* way to educate children with ASD, there is no *one way* to evaluate what will be the best combination of services for your child and your family. You need to be sure that your values and priorities guide your decision-making about services. You could say that as long as your child is making progress towards your most important outcomes, they are receiving the appropriate services.

As you work through this workbook, there may be some sections you are not able to fill in yet. That is okay! You may end up going through this book several times as you explore therapies, resources, agencies, and providers for your child. The information you want and the questions you have will change as your child grows and as you gain experience working with providers. It may be possible to fill some sections in on the first read-through, but you may need to come back to others later as you learn more from providers or agencies in your community. This is meant to support you in gathering the information you need to guide decision-making during this new time. You are not expected to remember everything but instead plan on coming back to this document and using it as a guide.

We encourage you to fill out the spaces with information that is specific to your child and family when you see this symbol. You may also consider adding any questions or notes that you have for when you meet with your care team!






PAUSE AND REFLECT: AN EXERCISE FOR PARENTS

First, it will help to write down all the therapy recommendations that you have received from professionals, read about yourself, or heard about from friends or online groups. As you learn more about and consider these recommendations, we suggest updating the list by rating the ones that you are most interested in pursuing. There is space throughout the book to take notes and additional pages for notes at the end.

Recommendations: In the following table, please write down the services that have been recommended for your child and/or family.

Therapies/services	Priority rating
	



Therapies/services	Priority rating
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[Large watermark graphic]	
[Large watermark graphic]	



- 1** _____
- 2** _____
- 3** _____
- 4** _____
- 5** _____



OVERVIEW: INTERVENTION

What it is and why it is important

When to start intervention?

The best day to start intervention is the day you start intervention. We know that young children benefit from individualized teaching. Learning happens throughout a child's entire life and each child will continue to have opportunities for growth and development at all ages. Research on early intervention suggests that better outcomes (more growth and learning) can result from starting intervention services at a very young age, but quick entry into services is not as important as finding a provider and agency that is a good fit for your child and family. Even though the professionals you are talking to may be experts in their field, YOU are the expert about your child and your family values and priorities.

My child's age at diagnosis:

My child's age today _____ on _____ (date):

My child's age at entry into autism-specific intervention services (fill this in later, once completed so you have a record):





Intensity vs. quality

One of the first questions that parents often ask is “How many hours of intervention does my child need?” Hours of intervention and intensity are actually two different things. There are no easy answers or formulas for deciding on the “right” level of intensity for your child. We suggest that you think about a few different things when deciding on what is best for your child. Most often, the word “intensity” is used to suggest the need for many hours of intervention, but this is not the only way to measure success (and for many children, it is not the best way either). The most successful intervention needs to include really good quality instruction for your child. A high number of intervention hours should be carefully weighed against the *quality* of the intervention *in those hours*.

An intervention program with a high number of hours that results in an overly tired and behaviorally disruptive child may be “intensive” but may lack *quality* because there are limited opportunities for learning when your child is upset. Similarly, high-quality learning opportunities that don’t happen often enough may hurt your child’s progress in learning new skills. The following section will help you consider the overall intensity of hours for your child and give you guidance for considering the impact of intensive hours as you move forward with adding new activities.

Hours per week my child is already involved in intervention. Include all organized activities in which your child currently participates (e.g., speech therapy, early intervention services, developmental preschool, etc.):

Hours per week my child is involved in other teaching/peer activities (Sunday School, daycare, music classes):



When is my child most successful?

During what activities or times of the day do my child struggle?

How many hours per week can I expect my child (who is 3 or younger) to be in intervention?

There is surprisingly little research that has focused on determining the best number of hours per week of ABA for young children. Based on our clinical observations, 12-15 hours per week of ABA is a common recommendation for young children. While this is a common recommendation and can be a good fit for many children, it does not mean that it will be a good fit for all children. It is important to consider your child's developmental needs (naps, playtime, family/community activities, outside time) alongside their needs for intensive intervention.

In many cases, it can be a good idea to start with a smaller number of hours and increase as your child is ready. It is also important to pay close attention to signs that your child is doing and listen to those cues - this also means that the therapists working with your child will need to be on board with recognizing and listening to these cues. All of these things need to be considered when deciding on a developmentally appropriate and achievable schedule for your child and you. We assume that your child has a pediatrician, Early Support for Infants and Toddlers (ESIT), or Birth to Three early intervention services providers, and you - don't forget to rely on collaboration among ALL providers to work in coordination for the best outcomes for your child. If your child is receiving services through ESIT, then you may already have a multidisciplinary team who can help support this effort with any new outside providers you are looking to add.





Move to one big table (as you think about adding a new intervention/ABA consider all of the things that you and your family are already committed to) Think about your whole family. It is okay if your morning yoga class is what gets you through the day - don't let that go! What are the things that you need to keep, and what can you let go of?

Activities/interventions my child is currently involved in:

Current hours per week of activities/interventions for my child _____.

Activities/interventions my other children or household members are involved in:

Current hours per week of activities/interventions for other children or household members _____.

Activities/interventions for myself each week:

Current hours per week of activities/interventions for myself _____.



Put a star next to the ones that are most important for you and your family/household members to keep doing. How many hours per week does that equal: _____

Do any important activities have flexibility for scheduling if necessary?

How many other interventions are you driving to/from? Consider the amount of time you and your child will need to spend in cars each week when all activities are occurring.

Individualization

Your child should have a unique intervention program with goals and strategies designed specifically to fit your child’s needs within your family and your daily routines and activities. Intervention program goals and priorities should be based on several things including (a) clinical assessments completed by your therapists, (b) your input and priorities, and (c) observations of your child in important daily activities and settings. The treatment plan that is created should include an individualized recommendation for intervention hours, goals that make sense to you and are important to your child and family - they should address areas of major needs you have, and should include a plan for your support and coaching from the therapist that feels like it is meeting your needs.



To be completed when ABA starts (best practices for this process):

Clinical assessment tool(s) used for my child (sometimes called a Curriculum-Based Assessment/CBA). This is not the diagnostic evaluation -- but an evaluation done by the BCBA who is your primary contact for intervention:

***If you don't know what this is, ask the BCBA!**

Behavioral observation of my child was conducted by _____ on _____ while my child was doing (write the activity and location here):

Parent interview was conducted by _____ on _____.

The main things that I would like intervention to focus on for my child are:

(To be completed after treatment plan or goals are shared with family)
List some of the goal areas included in the treatment plan or shared with me by provider:

Did providers include family priorities and goals?



What questions do I have?





Intervention type and teaching strategies

There are many ways of teaching, for children with autism, most are based on applied behavior analysis (ABA), with research to show they work. These are called evidence-based practices. Terms for some common ABA strategies for children under three with autism include the use of positive reinforcement, antecedent-based interventions, visual supports, modeling, differential reinforcement, and prompting. For definitions of these and a full list of evidence-based practices, visit:

<https://autismpdc.fpg.unc.edu/national-professional-development-center-autism-spectrum-disorder>.

Interventions using the principles of ABA have demonstrated the best outcomes, which usually means that kids made the most progress with these types of approaches. These treatment models focus on a range of target skills (across developmental areas and core ASD symptoms). For children under three, the recommendation is to use naturalistic, developmentally appropriate ABA strategies. Research on younger children suggests that interventions that are embedded into the child's routine and environment may be better than when kids practice skills in unfamiliar places. In behavior analysis, these are called Naturalistic Developmental Behavioral Intervention (NDBI) strategies.

However, as noted above, each program should be individualized to best meet the needs of the child and family. In order to do this, data must be collected and reviewed regularly by all team members AND a collaborative multi-disciplinary team approach should be used for the best outcomes. The following table explains important components of what Naturalistic Developmental Behavioral Interventions should include.

Component of an NDBI	What that means
Intervention is implemented in a natural setting	Intervention occurs in a setting where the child would spend time if not in intervention, such as in the child's home or daycare
Intervention involves shared control between the child and provider	The provider and the child both make decisions about which activities will happen. The child may choose the toys or materials to play with based on what is available in the setting or perhaps what has been pre-selected by the provider. The provider will then embed teaching into play with the materials chosen by the child.



Component of an NDBI	What that means
Intervention makes use of natural opportunities for learning	<p>This means that teaching is embedded into naturally occurring daily routines and activities. This can also mean that the number of practice trials may be lower than an adult-directed and more structured approach, but the learning opportunities are meaningfully tied to the child's routine and environment. This also refers to the type of reinforcement available for child responses to learning opportunities. Natural reinforcers, meaning reinforcement that is related to the activity, are used. For example, if a child wishes to go outside and walks to the front door, there could be opportunities to practice the routine of putting shoes on and then requesting non-verbally by pointing to the door and coordinating a glance near the adult to ask to go outside. The reinforcement would be getting to go outside!</p>



Component of an NDBI	What that means
<p>Intervention uses a variety of behavioral strategies to teach developmentally appropriate and pre-requisite skills</p>	<p>This means that the principles of the science of applied behavior analysis (ABA) are used to teach new skills. This involves examining the teaching of a new skill through a lens that looks at which environmental cues occur before the skill and which environmental changes result from that skill. The variables in the environment before and after a given skill can be modified to increase practice opportunities and reinforce it so that it happens more in the future. This is how we all learn! Targets of this approach for learning should be developmentally appropriate for the child and simpler or pre-requisite skills should be taught before more complex skills.</p>





Support for social interaction

During the early years, young children learn a lot about how to interact with other young children. Young children with ASD need to have opportunities to interact with typically developing children. Intervention for young children with ASD should provide intentional, systematic support to learn and practice developmentally-appropriate social skills with other children.

My child has opportunities for social interactions in the following ways:

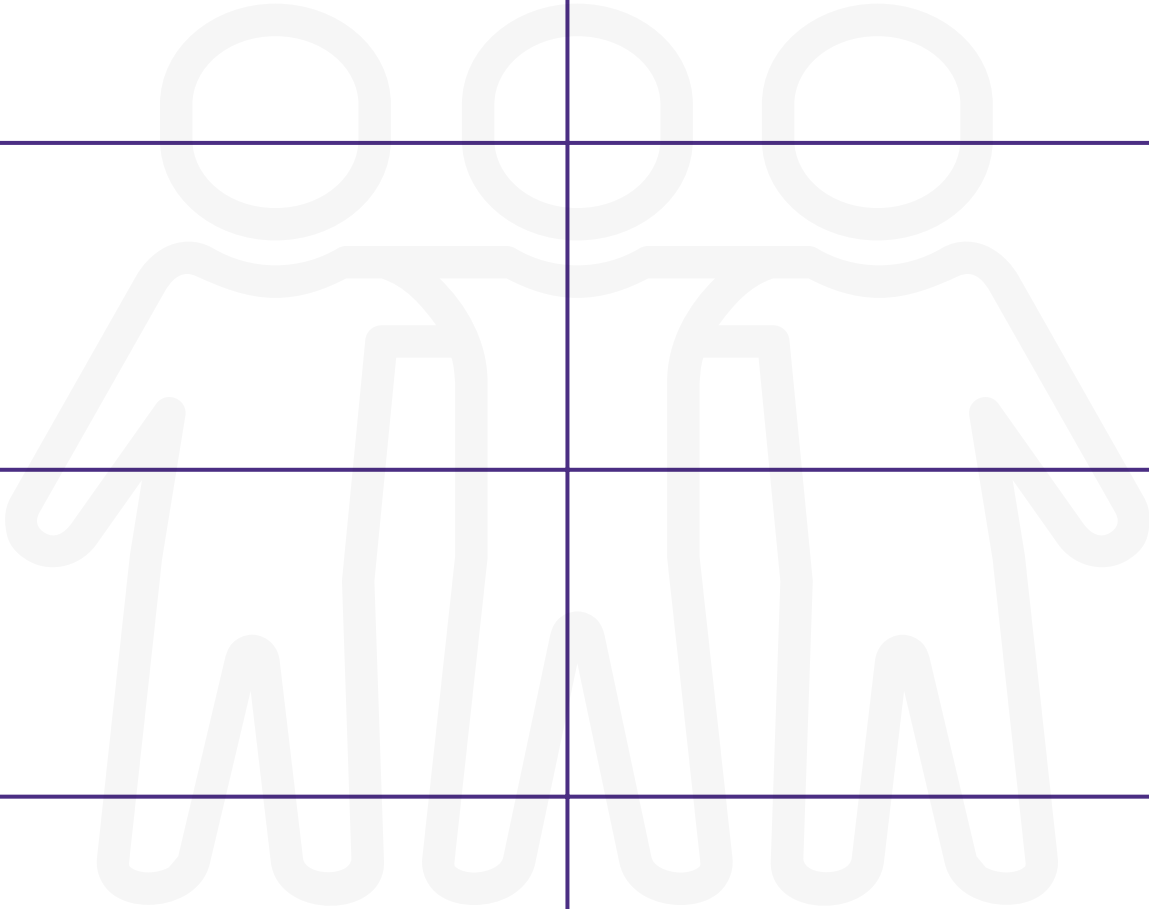
My child is involved in group settings in the following ways:

Collaboration and coordination

All intervention and service providers should regularly collaborate to ensure that intervention targets, strategies, and progress monitoring are coordinated. There is no single intervention approach or provider who has all the answers and all the training. An intervention team for your child should be made up of providers who have the expertise in areas of development your child needs support with, but who also understand your child's age and developmental needs and are willing to work with other team members to get the best results. Team collaboration can reduce stress and demand on parents, can lead to meaningful coordination of care, and will result in all team members being held to a high standard of serving your child.



My child's team members (fill this in as you add new people)	Approach to collaboration (Discuss the importance of this with each provider and write notes on their responses)





Data and progress measurement

Child progress on target skills should be measured frequently, data should be summarized, and treatment decisions should be made based on progress; providers should work with families to ensure that child progress is meaningful. As parents, it is important that you get a chance to see the data, ask questions, and speak up about your priorities.

Provider	How data are recorded	How often data/progress is shared with me





HOW TO MAKE A DECISION ABOUT PROVIDERS?

Questions to ask:

- Are there agency policies around minimum requirements for intervention hours (e.g., all clients must receive 40 hours a week, and all clients must be co-treated by the SLP and OT)?
- Does the agency ask you to take your child out of school for services?
- Does the agency ask you to restrict activities or routines that are important for you and your family?
- Are agency representatives available to answer your questions?
- Are agency services and policies culturally sustaining?
- What is the agency policy about multiple languages? Do they provide interpreters and translation of materials?
- Is the agency willing to be flexible and responsive to the needs of your family?
- Does the agency have requirements for minimum session length? Sometimes agencies have a minimum session length of time (such as 2, 3, or even 4 hours).
- Does the agency have policies related to coordination of care and collaboration between service providers? Collaboration is an essential part of effective intervention for very young children.

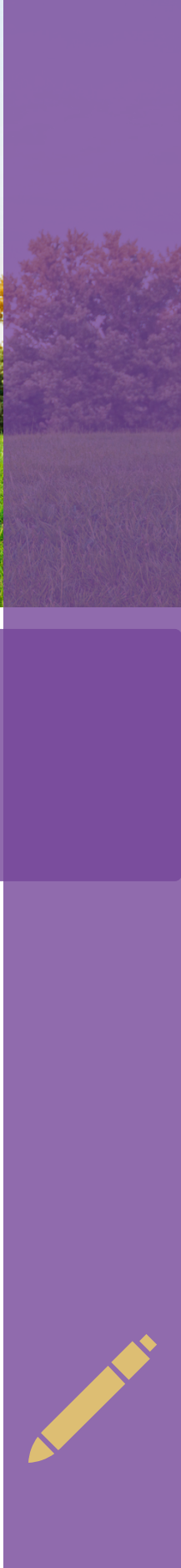


CONSIDERATIONS BASED ON FAMILY VALUES, PRIORITIES, AND RESOURCES

The following section is aimed at helping families consider factors that may be of importance based on individual family needs, parent/caregiver needs, or could perhaps influence a good provider fit. In this section, it may be helpful to write a list of pros and cons or jot down notes about preferences, concerns, values, and priorities.

Intervention is very important, but many influencing factors need to be considered when making decisions about starting new interventions.

Family needs and resource needs outside of child-specific intervention	Space for notes about unique family needs and resource needs:
Parent health supports:	



Family needs and resource needs outside of child-specific intervention	Space for notes about unique family needs and resource needs:
Basic needs such as food, utilities, rent, transportation, etc.:	
School or therapies for other family members:	
Other needs:	





Family comfort with outside providers

Depending on the intervention approach, providers may be spending a lot of time with your child and perhaps a lot of time in your home. It is important to think about how comfortable you will feel with this type of intervention. Some providers offer services in clinical settings, and some can come to your child's daycare, but home-based services are often recommended to support the generalization of skills. Think about questions or concerns that you may have about the location of services.

Use this space to write notes about your thoughts on having another person...

In your home:

Spending lots of time with your child:

Insurance

Most insurance will pay for intervention services recommended for young children with autism. Your insurance carrier should be able to provide you with a list of in-network providers that you can contact about services. There are often waiting lists for these types of intervention services. Families often place their children on many waiting lists for services.





Family language

The University of Washington Autism Center has a helpful handout with more information on this topic. In general, the family/native language is very important for many reasons and generally should not be discouraged by providers. Link to the handout here: <https://depts.washington.edu/uwautism/wp-content/uploads/2019/06/BilingualismASD-Handout-Final-Draft.pdf>

Family cultural beliefs and practices

Providers should seek to understand and respect your family cultural beliefs and practices. This should look like providers asking questions (“Should I remove my shoes in your home?” “Are there locations in your home that are off limits for intervention?” etc.). It should also mean that providers take measures to remember what has been shared and respectfully follow your cultural practices when in your home. If there are conflicts between cultural practices and the intervention approach, they should be resolved in a communicative team approach that is guided by parent feedback for family cultural practices.

Use this space to list cultural beliefs, practices, or preferences as well as family norms in your home:



Use this space to list cultural beliefs, practices, or preferences as well as family norms in your home:



Family religious beliefs and practices

As above, providers should seek to understand and respect family religious beliefs and practices when in your home. Similar questions and measures as mentioned in the above bullet should be applied to religious beliefs as well.

Use this space to describe important religious practices, beliefs, and considerations that may be important for providers to be aware of while working in your home and with your child. *Some possibilities include dietary restrictions, holidays that involve fasting or canceling sessions, preference for not including art projects or books about holidays in intervention, etc.*





Caregiving beliefs, styles, and practices

It is important to identify your parenting/caregiving beliefs, styles, and practices. While this is helpful to do prior to starting intervention services, it isn't necessarily the only time it is helpful. If at any time your caregiving radar sounds and you feel unsure about a specific intervention goal or instructional strategy, talk with your provider. During this conversation, share what made you unsure and ask clarifying questions so that you can better understand the reason for the goal, instructional strategy, etc.

Describe your beliefs about parenting, your approach to parenting, or your style of parenting. This can include examples of your interactions with your child. What types of things do you believe in teaching or modeling for your child? How do you believe in teaching these things?

Are there parenting styles or beliefs that you disagree with? Why?





Family information preferences

How does your family prefer to share information? Share with your provider that this is important to you and the ways in which you and other caregivers (and siblings or other family members) learn best.

Some examples of preferred forms of information sharing include: discussion, video examples, reading, email reminders, live practice, workshops, etc. List some ways that you and other family members learn best. When you are expected to learn something new about your child's intervention, refer back to this list and ask for specific support in the way you learn best!

Neurodiversity perspective

Adult self-advocates, based on personal experience, have been helpful in illuminating how the intervention may feel to the child, for providers. The University of Washington Autism Center has a helpful handout for questions and considerations guided by the perspectives of adult self-advocates. Link to handout: <https://depts.washington.edu/uwautism/wp-content/uploads/2021/07/Finding-the-Right-Autism-Services-for-Your-Child.pdf>





CONSIDERATIONS BASED ON CHILD CHARACTERISTICS

Strengths

Providers should ask questions about your child's strengths and passions. You may be familiar with ways that your child learns best already, share what you know and have experienced with your provider!

What have you noticed about how your child learns new things? Does your child try and try until they master something on their own? Does your child prefer to watch before trying? List some examples below about things you have witnessed your child learn and the process they went through (this includes you teaching them) to get there.





Areas of need

What areas of development would you like to see addressed by your child's program?

Challenging Behaviors

Does your child engage in behaviors that are dangerous or interfere with family routines? Is this something you are hoping your provider can support you with?

If so, it is important that your provider first seeks to understand the reason why your child engages in these behaviors and develops plans to address them accordingly. These plans should strongly emphasize teaching replacement communication for the challenging behavior as well as other age-appropriate adaptive skills to increase your child's functioning so they can better meet their needs.



Does your child engage in challenging behaviors that disrupt learning?

Did your provider discuss these behaviors with you as well as the steps that will be taken to address them?

If not, ask your provider if this can or will be included in the intervention approach - let them know if you feel that you need help.



Priority intervention goals

Intervention goals should be selected based on a number of factors such as a curriculum-based assessment, behavioral observation of your child, and interviews/discussions with caregivers. Targets should also be meaningful to your child's life and environment. Priorities should be given to goals that are functional, improve access (to environments, activities, social interactions, etc.), and should not be chosen for ease of instruction or only selected off a list of skills in chronological order.

Do all of your child's treatment goals make sense to you? *If not, ask your provider why certain goals were chosen for your child.*

Did the provider explain why certain goals were chosen when you asked? Did the answer make sense to you?

Do you feel comfortable with the treatment goals for your child?

Are there goals/areas you were hoping to address that were not included in the treatment goals? *If yes, ask your provider about them and if they can include them in the treatment.*

Did your provider modify the treatment goals to include your areas of concern? If not, did the provider give an explanation as to why these were not included and when or how they may be addressed in the future?





NOTES & QUESTIONS

Consider writing down your questions for when you meet with your care team!

What questions do I have?





NOTES & QUESTIONS

Consider writing down your questions for when you meet with your care team!

What questions do I have?

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NOTES & QUESTIONS

Consider writing down your questions for when you meet with your care team!

*What
questions do I
have?*

