

# Caregivers' Guide

## Transitioning Out of EI for Children with Autism

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*Early Intervention services are scheduled to end on your child's 3rd birthday. Service Coordinators usually initiate the transition process six months before your child's 3rd birthday. Regardless of where you are in this process, it's never too early or too late to plan ahead for life after EI.*

## The Purpose of this Guide

This guide is designed to assist caregivers (including parents, grandparents, aunts or uncles, foster parents, etc.) of children diagnosed with an Autism Spectrum Disorder who live in Massachusetts with their transition out of Early Intervention (EI). The material included in this guide is based on the “Almost 3” Autism Transition Tool, which is a web-based survey-style questionnaire. You can access the “Almost 3” Autism Transition Tool at [www.autismtransitiontools.org](http://www.autismtransitiontools.org).

The purpose of this guide, as well as the webtool, is to accomplish the following;

- 1.) To compare current services and supports in EI with the services and supports that will be in place after your child transitions out of EI.
- 2.) To identify areas where support might be lacking in the future.
- 3.) To provide information about some resources that might be helpful in navigating your child’s transition and implementing supports for the future.
- 4.) To provide suggestions about how to utilize current providers in creating a strong, supportive network of services and community connections for your family.

It is strongly recommended that you consider using the “Almost 3” Autism Transition Tool at [www.autismtransitiontools.org](http://www.autismtransitiontools.org), particularly if you find this guide helpful.

## About This Guide

This guide and the “*Almost 3*” *Autism Transition Tool* were created by O. Sophia Johansson, the parent of a child with ASD. She worked in conjunction with other parents and professionals in the field to produce a resource she believed was missing when her family transitioned from EI into the public school system. Sophia completed this project as part of the Early Intervention Parent Leadership Project’s first-ever Family Leadership Training Series, funded by the Massachusetts Department of Public Health.

This resource was originally based on, “Starting Points for Service Coordinators for Children with Complex Care Needs,” and, “Starting Points for Service Coordinators for Children with Hearing Loss.” The creation of this resource was inspired by Sophia’s social worker in EI, a pretty amazing woman who not only helped her get through that first year of her child’s diagnosis, but also inspired her to channel her problem-solving skills into forms of advocacy that would support other caregivers.

## Comparing Services and Supports

*Complete the table on page 5 according to the instructions below.*

**“Hours Per Week currently”** should include both the hours you are receiving in EI and the hours you are receiving outside of EI. For example, if you are receiving 1 hour of speech therapy in EI and 2 hours of speech therapy through a provider at a local clinic or hospital, then you would enter “3” as the total number of hours of Speech Therapy your child is receiving.

**“Hours Per Week in the IEP”** should include the hours specified in the service grid of your child’s Individualized Education Plan (IEP). If you are not yet familiar with what an IEP is or have yet to review what the Team is proposing for your child’s IEP, you can learn more about this process on [page \[x\]](#).

**“Hours Per Week privately”** should include the hours you are certain will remain in place once your child has transitioned from EI. For example, if your child is currently receiving 2 hours of speech therapy through a provider not associated with EI and will continue to receive 2 hours of speech therapy after EI ends, then enter “2” in this column. However, if your child is currently receiving 2 hours of speech therapy through an independent provider and will only receive 1 hour of speech therapy from this provider after EI ends, then you would enter “1” in this column.

**“Hours Per Week in the future”** is a number you must calculate on your own. Simply add the number of hours in the “Hours Per Week in the IEP” with the “Hours Per Week privately.” For example, if the service grid in your child’s IEP specifies 1 hour of speech therapy each week and your child will also receive 2 hours of speech therapy outside of school through a private provider, then you would enter “3” in this column.

**“Total hours currently”** is a number you must calculate on your own. Simply add all of the values in the column and enter that number. For example, if your child is receiving 1 hour of speech therapy, 10 hours of ABA, 1 hour of OT, and sees his or her Service Coordinator for 1 hour each week, then you would do the following math;

$$1 + 10 + 1 + 1 = 13$$

You would enter “13” as the value in “Total hours currently.”

**“Total Hours in the future”** is calculated the same as, “Total hours currently.”

The therapies, services, and supports included in the table on page 5 are just an example of what your child may be receiving. Some of the therapies, services, and supports might be relevant to your child’s needs while others may not. You may also find that there are some therapies, services, and supports missing. You are welcome to add those in the cells titled, “**Other.**” You might also notice that some boxes contain an, “**x.**” This is because those services are not typically included in an IEP.

Service or Support	Hours Per Week currently	Hours Per Week in the IEP	Hours Per Week privately	Hours Per Week in the future
Speech therapy				
Applied Behavioral Analysis (ABA)				
Occupational Therapy (OT)				
Physical Therapy (PT)				
Music Therapy		X		
Social Skills Group or Play Group				
Social Worker		X		
Service Coordinator		X		
Other:				
Other:				
Other:				
	<b>Total hours currently:</b> _____			<b>Total hours in the future:</b> _____

*Proceed to the following page for information about how to use this table.*

## **Why Compare Services and Supports?**

When your child entered Early Intervention, your family underwent -- and might still be undergoing -- a significant transition. Your community suddenly included more than just your family, friends, and neighbors; when you started EI, you also began a relationship with numerous providers and specialists. These new members of your community were there to support your child's development and to support you, as well as your family, in helping your child grow and develop. When EI ends, your family will undergo another significant transition. When your child turns 3, they are no longer eligible for EI. Instead, they are eligible for services and supports through the local school district.

There are two priorities to focus on when thinking about life after EI:

1. Your child's rate of progress should remain the same or increase.
2. Your family has sufficient support going forward.

The purpose of EI is to support your child's development. Children on the autism spectrum are developmentally delayed in numerous areas. The best outcomes for these children occur when they experience numerous supportive, positive, therapeutic interventions at a young age. When your child began EI, they might not have been verbal or may have had significant motor delays. And while your child might still be non-verbal, or might continue to have significant delays in their gross or fine motor skills, they have certainly gained skills since they began receiving services from EI. It is important for your child to continue to gain skills.

The rate that your child gained skills in EI may or may not be representative of what to expect in the future. Some children with autism can regress, or lose skills, when they age. Often times, children are capable of at least maintaining the rate of progress, or the rate at which they acquired new skills in EI. Some children might be capable of a greater rate of progress or skill acquisition. For example, if a child only received 1 hour of speech therapy a week in EI, but will be receiving 1.5 hours each week in school, it is likely that their rate of progress will increase.

Generally speaking, the best predictor of a steady rate of progress is maintaining a consistent amount of services, supports, and therapies. Comparing the, "Total hours currently," with the, "Total hours in the future," (in the table on page 5) provides a preliminary look at whether or not your child will likely maintain the same rate of progress. There are, however, a tremendous amount of variables to consider when using any type of equation.

Your child is a unique individual with needs unique unto his or herself. Furthermore, your child will continue to grow and change with time. At some points, once area of

development might require a lot more attention than another. It is possible that your child might make considerable strides in one area of his or her development, only to slow in another. It is also likely that his or her rate of progress will be variable over the course of a single year, simply because of the changes from a summer schedule or school vacation schedule to a normal school week.

## Some IEP Basics

Define IEP in general.

Describe “Team”

Children with a diagnosis of an Autism Spectrum Disorder, or a related disability like Pervasive Developmental Disorder - Not Otherwise Specified or Asperger’s Syndrome, are automatically eligible for an IEP because they are considered to have a disability.

Describe process of creating an IEP.

When a child on an IEP has an Autism Spectrum Disorder, the school’s Team must consider the following areas of the child’s development;

- Verbal and non-verbal communication
- Skills regarding social interaction
- Sensory needs and ability to regulate his or her own sensory system
- Child’s response to environmental changes or changes in the daily routine
- Repetitive activities or stereotyped movements
- Positive behavioral interventions to address behavioral difficulties
- Any other needs that may affect the child’s progress in the general curriculum and his or her social-emotional development



## **Your Team of Specialists**

Some families of children on the autism spectrum use their insurance benefits (or pay privately) for the services of various specialists to help manage the child's medical, developmental, and therapeutic needs. What follows is a list of specialists and a description of their expertise. This list is not meant to represent every type of specialist that's out there. It's a list of *some* specialists commonly utilized by caregivers of children with autism.

When your child transitions out of EI, your team of specialists will be there to follow your child's development and to help you determine what your child needs going forward. They can provide valuable support once your child transitions out of EI. These same specialists can also advocate on your child's behalf if any changes are needed to your child's IEP.

**Primary Care Physician (PCP)** - This is your child's primary doctor. They are responsible for following your child's overall development, including their basic health needs. When your child is sick, you call him or her. If you need a referral for a specialist, you call his or her office.

**Developmental Pediatrician**

**Neurologist**

**Gastroenterologist**

**Psychiatrist**

**Psychologist**

**Speech Language Pathologist**

**Occupational Therapist**

**Physical Therapist**

**Board Certified Behavior Analyst**

**Play Therapist**

## Helpful Resources

Autism Insurance Resource Center

Contact info

What it's useful for

Early Intervention Parent Leadership Project

Contact Info

What it's useful for

Family TIES of Massachusetts

Contact info

What it's useful for

Federation for Children with Special Needs

Contact info

What it's useful for