

# Caregivers' Guide

• *draft* •

## Transitioning Out of EI for Children with Autism

### Contents

THE PURPOSE OF THIS GUIDE.....	2
ABOUT THIS GUIDE.....	2
COMPARING SERVICES AND SUPPORTS.....	3
SUPPORT GRID .....	4
WHY COMPARE SERVICES AND SUPPORTS? .....	5
SOME IEP BASICS .....	7
YOUR TEAM OF SPECIALISTS .....	9
HELPFUL RESOURCES .....	10

*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.*

## *Draft version.*

*Feedback can be addressed to o.sophia.johansson@gmail.com*

### **The Purpose of this Guide**

This guide is designed to assist caregivers (including parents, grandparents, aunts, 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.

The purpose of this guide, as well as the online tool, 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 independently with significant input and direction from 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 Service Grid on the next page 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.

***Draft version.***

*Feedback can be addressed to o.sophia.johansson@gmail.com*

**Support Grid**

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:				
	Total hours currently: _____			Total hours in the future: _____

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

It is important to review the services and supports you currently have with what you are looking forward to after your child transitions out of EI because doing this can help you identify two key things:

1.) Whether or not your child's rate of progress will remain the same (or increase).

2.) Whether or not your family has sufficient support going forward.

When EI concludes, you, your family, and your child will no longer have the same supports in place. It is up to you to recognize the gaps and determine how to fill them. The best place to begin is by comparing the services and supports that are currently in place with what you are expecting will be in place in the future.

Generally speaking, the best predictor of a child's steady rate of progress throughout their early childhood is maintaining a consistent amount of services, supports, and therapies. Comparing the, "Total hours currently," with the "Total hours in the future" in the Support Grid on page 4 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.

Your child is a unique individual with needs all his or her own. At some points, one area of your child's development might require 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 that of a normal school week.

Furthermore, 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. 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, then it is likely that their rate of progress will increase.

***The amount of your child's services and supports in EI are the same as what you are expecting after EI:***

While the amount of services and supports your child will receive will remain the same, the *types* of services and supports might change. You can use the table to identify where your child's services and supports will decrease or increase.

It is also important to remember that while the Support Grid represents a

## **Draft version.**

*Feedback can be addressed to o.sophia.johansson@gmail.com*

consistency in supports and services that your child will also be attending school. If you subtract the amount of services your child will receive in school from the total number of hours they are scheduled to be in school each week, then you will have a bit more of an accurate picture of the supports and services they are receiving.

Your child's rate of progress will likely stay the same based simply on the number of hours he or she will receive after EI. If you would like to see his or her rate of progress improve, you could focus on the areas where your child has the greatest challenges and increasing support and services in that particular area of development. You might also consult your team of specialists outside of EI to see if anyone believes your child should be making more progress in any particular area of his or her development.

However, many families of children with Autism often find the amount of services and supports their children receive to be overwhelming, especially when combined with such a rigorous schedule of interventions. If you find that your schedule is taxing, it might be good to revisit increasing services at a time when you're less overwhelmed. Conversely, you might never feel the need to consider increasing services and supports for your child. This decision is perfectly acceptable.

***The amount of your child's services and supports in EI are more than what you are expecting after EI:***

You can use the table to identify where your child's services and supports will increase. And while the Support Grid represents an overall increase in supports, some of your child's services and supports might be decreasing.

If you have purposefully increased the amount of services and supports that your child will receive after EI, then you have probably done an excellent job accessing all the resources that are available to you. Nonetheless, it might be helpful to review where your child will see an increase in services with your Service Coordinator and your child's team of specialists outside of EI. It's important to ensure that all areas of your child's development and all of his or her needs are met. Sometimes we, as parents or guardians, might focus on one particular area where our child is delayed at the expense of supporting another area of his or her development. Regardless, it's clear that you are actively seeking out the resources available to support your child's development.

***The amount of your child's services and supports in EI are less than what you are expecting after EI:***

You can use the table to identify which areas your child's services and supports will decrease.

It is also important to remember that while the Support Grid represents a decrease in supports and services that your child will also be attending school. If you subtract the amount of services your child will receive in school from

## *Draft version.*

*Feedback can be addressed to o.sophia.johansson@gmail.com*

the total number of hours they are scheduled to be in school each week, then you will have a more accurate picture of the supports and services they will receive after EI.

If you have purposefully decreased the amount of your child's interventions, you might consider discussing this with your Service Coordinator or some of the specialists that work with your child outside of EI. It will be important to monitor your child's rate of progress to ensure that they continue to gain skills at least at the rate that they did in Early Intervention.

If this isn't a purposeful decision, you have a couple of options available to you. You can pursue additional services privately through your health insurance benefits, or you can explore your options for modifying your child's IEP so that they receive more services, or you can do both.

If you'd like more information about the IEP process or about working with the school district to modify your child's IEP, you can contact the Federation for Children with Special Needs at (617) 236-7210 or (800) 331-0688 (in MA only).

## **Some IEP Basics**

*The information below was significantly informed by materials created by the National Dissemination Center for Children with Disabilities, a federally funded program whose funding ended on September 30<sup>th</sup>, 2013.*

It is highly recommended that you contact the Federation for Children With Special Needs (see "Helpful Resources") to learn more about the IEP process or attend one of their free information sessions. The information sessions that you would probably find the most helpful are, "Turning Three," "Basic Rights," and "The IEP."

An Individualized Education Program (IEP) is a written statement of the educational program designed to meet a child's individual needs. Every child who receives special education services must have an IEP. The two general purposes of the IEP is to do two things;

1.) To set reasonable learning goals for a child.

2.) To state the services that the school district will provide for the child.

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.

Parents, legal guardians, and providers in the EI system are some examples of the people who can recommend a child for an evaluation to determine whether or not a child requires special education and related services. Once these evaluations are conducted, the IEP is developed. A team develops the IEP together. This group of individuals includes specialists within the school

## ***Draft version.***

*Feedback can be addressed to o.sophia.johansson@gmail.com*

district, program administrators or coordinators, and a child's parents. The team convenes, reviews the information gleaned from the evaluations and assessments done by the school district and any additional evaluations that the parents submitted, and then designs an educational program to address the child's educational needs. Often times, school districts bring a draft of a proposed IEP to this meeting. Parents can accept, partially accept, or reject the IEP as it is proposed.

IEPs must be reviewed annually, according to federal law.

### ***Content of an IEP***

Each child's IEP must include specific information, as listed within the Individuals with Disabilities Education Act (IDEA).

IDEA is a law ensuring services to children with disabilities throughout the USA. IDEA governs how states and public agencies provide early intervention, special education and related services to infants, toddlers, children, and youth with disabilities. Children and youth (ages 3-21) receive special education and related services under IDEA Part B.

IDEA states that an IEP must include, but is not limited to, the following;

- The child's present levels of academic achievement and functional performance.

- Annual goals for the child that represent what the parents and school team believe he or she can reasonably accomplish in a year.
- The special education and related services to be provided to the child, including supplementary aids and services (such a communication device) and changes to the program or supports for school personnel.
- How much of the school day the child will be educated separately from nondisabled children or not participate in extracurricular or other nonacademic activities such as lunch or clubs.
- How (and if) the child is to participate in state and district-wide assessments, including what modifications to tests the child needs.
- When services and modifications will begin, how often they will be provided, where they will be provided, and how long they will last.
- How school personnel will measure the child's progress toward the annual goals.

### ***IEPs for Children with Autism***

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;



### *Draft version.*

*Feedback can be addressed to o.sophia.johansson@gmail.com*

- 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**

- Primary Care Physician
- Developmental Pediatrician
- Neurologist
- Gastroenterologist
- Psychiatrist
- Psychologist
- Speech Language Pathologist
- Occupational Therapist
- Physical Therapist
- Board Certified Behavior Analyst (BCBA)
- Special Education Advocate
- Play Therapist

This list is not meant to represent every type of specialist that exists, or even every type of specialist your child should work with. This is 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 as he or she ages. They can provide valuable support when EI ends. These same specialists can also advocate on your child's behalf if you need to modify your child's IEP.

## **Community-Based Connections**

Community-based connections include your social supports and your connection to organizations, be they religious or recreation-based that are local to you and your family.

Raising a child with Autism can be stressful, overwhelming, isolating, and uniquely rewarding. It is important to establish and maintain connections with people who can understand this and support you and your family. Many caregivers find support groups or parent groups (focusing on caregivers of children with special needs or children with Autism) offer valuable opportunities to connect with other caregivers. There are support groups for grandparents raising grandchildren, foster parents, adoptive parents, and nearly any other type of caregiver you can imagine. As the name suggests, support groups usually rely on a number of people gathering together. For some individuals, this is a very effective means of garnering support. For others, this format might not be ideal or a support group might not offer enough one-on-one support.

For individuals who prefer a more one-to-one opportunity to connect, Family TIES of Massachusetts hosts a Parent-to-Parent program that connects caregivers. Individuals can contact

Family TIES and request a parent match. You can learn more about Family TIES of Massachusetts and the Parent-to-Parent program in the “Helpful Resources” section of this guide.

Community-based recreation programs can also offer your child meaningful opportunities to connect with other peers in a structured environment. These same programs are also opportunities for your child to experience different types of physical activity (regardless of their gross motor abilities or impairments). Many towns have recreation departments that were created to serve residents. Sometimes, there is a recreation therapist on staff whose job it is to create and run recreation opportunities for individuals with disabilities or special needs. The YMCA is another great option for exploring potential recreation opportunities. This is an organization that prioritizes serving individuals with disabilities and they have a strong model of inclusion. If neither of these exists close to you, you can talk with your Service Coordinator about some potential options that might exist, or you can inquire about options that might be familiar to your regional coordinator at Family TIES of Massachusetts.

## ***Draft version.***

*Feedback can be addressed to o.sophia.johansson@gmail.com*

If you are involved with a religious organization, like a church, synagogue, or mosque, you probably gain great strength from this connection. It is also likely that you are looking forward to your child gaining a similar type of strength from his or her participation in religious activities. Many religious organizations offer religious education. You may or may not have been expecting your child to participate in this type of programming.

Sometimes, caregivers encounter challenging experiences when their children with Autism are involved in religious education. When children are young, there are fewer expectations

placed upon them and there is oftentimes a very inclusive experience for all children. Based on these early years, it can be easy to assume that the inclusivity of religious education will persist as your child ages. If your child is having a positive experience, or if your child is not having a positive experience (or any experiences at all because your religious community does not embrace children with disabilities), then perhaps you might want to think about what would make your child's experience positive or what key elements are in place that will guarantee that your child's religious education will continue to be a positive experience.

## **Helpful Resources**

*This list of resources is not meant to be all-inclusive. These are all organizations that are equipped to answer many of your questions and connect you and your family with more resources, should you need them.*

**Autism Insurance Resource Center**  
[www.disabilityinfo.org/arica/](http://www.disabilityinfo.org/arica/)  
800-642-0249  
781-642-0248

The Autism Insurance Resource Center provides information to the public about insurance coverage under a new law, An Act Relative to Insurance Coverage for Autism (ARICA), which took effect in Massachusetts on January 1, 2011. There are many questions relating to the implementation of the law, e.g., to whom, ARICA applies,

what treatments are covered and how to access coverage. The Center, a new program of New England INDEX, is designed to provide information and support for self-advocates, family members, providers, employers and educators on issues related to medical insurance for autism treatment.

**Early Intervention Parent Leadership Project**  
[www.eiplp.org](http://www.eiplp.org)

## *Draft version.*

*Feedback can be addressed to o.sophia.johansson@gmail.com*

1-877-35-EI-PLP  
eiplp@yahoo.com

The Parent Leadership Project, a project of the Office of Family Initiatives at the Massachusetts Department of Public Health, was created to support parents whose children receive early intervention services. The Project's main goal is to promote lifetime advocacy, leadership skills and the development of an informed parent constituency, which will encourage early intervention services to be increasingly family centered. The Project is a parent driven endeavor, which continually seeks family involvement and input regarding the needs of families enrolled in Early Intervention and is implemented by parents whose own children have received EI services.

**Family TIES of Massachusetts**  
[www.massfamilyties.org](http://www.massfamilyties.org)  
1-800-905-TIES

Family TIES of Massachusetts provides information and referral services, emotional support, and trainings to parents of children and youth with special needs - just like you, we are caring for our children and aim to light your way.

Family TIES of Massachusetts is also home to the ***Parent-to-Parent Program***, which brings together parents facing similar challenges in raising their children with special

needs. Parents contact our staff and say they want to talk to another parent. The Regional Coordinator will share a Match Request form. The process begins when a completed form is received by the Parent-to-Parent Program. Staff will confirm the form is received, then search our database of trained volunteers, to find a Support Parent to offer a listening ear. The Match consists of phone contact between the parent seeking support and the Support Parent. Often, requests are focused on issues such as a child's diagnosis or developmental stage; life activities such as recreation, childcare issues, or developing friendships; finding support in your area of the state; or sibling concerns.

### **Federation for Children with Special Needs**

[www.fcsn.org](http://www.fcsn.org)  
529 Main Street, Suite 1M3 Boston, MA 02129  
Phone: (617) 236-7210, (800) 331-0688 (in MA)  
Fax: (617) 241-0330  
[fcsninfo@fcsn.org](mailto:fcsninfo@fcsn.org)

The Federation for Children with Special Needs provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities. The Federation is home to many programs and projects, the following of which are just some that they house.

### ***Draft version.***

*Feedback can be addressed to o.sophia.johansson@gmail.com*

The ***Special Education Parent Center*** focuses on providing support, information, training and workshops related to special education to families of children with special needs (includes our outreach programming to culturally and linguistically underserved families). Through a variety of activities, parents can learn about the special education process (including IEP, Basic Rights, Transition Planning, MCAS, etc.) so that they can best support their child. Additionally, parents can participate in an intensive 8-week in-depth training on special education policy and procedures. Projects include: Parent Training and Information Center, Transition/Planning a Life, Community Outreach and Empowerment Project, and the Parent Consultant Training Institute.

The ***Family Support Center*** focuses on providing parent to parent support for

families who have children with special health care needs or disabilities; women, children, adolescents and young adults infected/affected by HIV/AIDS; families of young children with early childhood mental health issues; and families who have a serious mental health challenges and complex DCF cases with child custody concerns.

The ***Health Advocacy Center*** focuses on providing healthcare information and support to families of children with special needs, and programming that helps build capacity for family partnerships and supports partnership activities between managed care organizations and parents around improved access to services and supports. Projects include Mass Family Voices, Family-to-Family Health Information Center, and the Massachusetts' Children's Health Insurance Program Act (CHIPRA).

### **We're always interested in hearing from you!**

If you've got feedback about this guide, or would like to get in touch for any reason, you are welcome to email the author, O. Sophia Johansson, at o.sophia.johansson@gmail.com.

*Please remember to try the online tool at [www.AutismTransitionTools.org](http://www.AutismTransitionTools.org).*