

Juana's Guide for Florida Parents with Neuro-Diverse Children

Dear Parents,

I remember being a new mother and receiving the diagnosis of autism for my son, Manu. I remember clearly how difficult it was to navigate the process of getting resources for him. I decided to put together this document because I wish someone would have helped me understand my child and how to get the best resources for him. I know I may not have all the answers, but I hope this document is helpful. We learn more together, and this is a time where you will need a community more than ever. Please feel free to reach out with comments and questions as we try to make this document better and more accurate.

Before I start, I want to remember that every child within the autism spectrum is different, and this is only Manu's story. When Manu was a baby, he seemed to be developing neurotypically until I noticed he was regressing on some of the important child development milestones he had already achieved. I took him to the pediatrician, who sent me to many specialists to review his case, but they didn't find anything physically concerning. I was frustrated because I didn't know what to do or what help was available for Manu and for me. Finally, I heard from another mother who had given birth prematurely and needed help with her child. She suggested that I find out what early intervention programs my county offered. This is how I learned about Easter Seals Treasure Coast in Palm Beach County. Through that program, we received free therapy for Manu, parent training resources for my husband and me, and--more importantly--we also received a diagnosis.

After Manu aged out of Easter Seals Treasure Coast, we were referred to Child Find, which is an organization that helps transition between early intervention and the school district's services. At Child Find, we received our first Individualized Educational Plan (IEP)--a document designed to support your child's learning and development in the school setting. This document is updated yearly until your child graduates high school.

As I'm writing this, Manu is eight years old, and is about to enter 2nd grade. I know we wouldn't have made it this far if we hadn't had access to the resources available to us.



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Here is a more detailed list of suggestions based on our journey with Manu:

1. Early Intervention Program: Research and contact the local Early Intervention Program in your state, which, in Florida is called Early Steps. Remember it was through them that we received a diagnosis. Early intervention in Florida is from birth to 3 years old. Here is more information on early intervention, along with suggestions for how to navigate services:

- The Center for Disease Control's information page on early intervention, with links to individual states:
<https://www.cdc.gov/ncbddd/actearly/parents/states.html>
- The Center for Disease Control's checklist of developmental milestones:
https://www.cdc.gov/ncbddd/actearly/pdf/checklists/Checklists-with-Tips_Reader_508.pdf
- CARD (Center for Autism and Related Disabilities):
<http://www.fau.edu/education/centersandprograms/card/> (I also recommend researching other local organizations that help and guide parents)
- Florida's Early Intervention System:
<http://www.floridahealth.gov/programs-and-services/childrens-health/early-steps/index.html>
- I created different binders to help me organize all of the Early Steps reports and progress documents, plus the information from CARD. For instance, I had separate binders for Manu's diagnosis, Applied Behavior Analysis reports, Individualized Education Plans, etc. These binders were very helpful to me because I knew what was the status of every service/resource that I was applying for. It was also helpful because I used it to help organize my to-do list.

2. The Diagnosis: As mentioned above, here in Florida, Early Steps provides a diagnosis through testing. If you want a second or third opinion, I suggest a neurologist, Psychologist, a developmental/behavioral pediatrician.

- Why is the diagnosis so important? You need a diagnosis to be able to go to your insurance company and prove that you need Applied Behavioral Analysis Therapy (ABA), Occupational Therapy, Speech Therapy and Physical Therapy for your child. If they deny coverage or if you need more hours of therapy than they say they offer, I encourage you to contact the claims department; if they deny it again, start an



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3. Child Find: Early Steps referred us to Child Find, which is a transitional tool between Early Steps and the school district. You can learn more about Child Find here: <http://www.fdlrs.org/departments/child-find>.

- They will develop your child's first IEP (Individualized Education Plan). For your first meeting with the Child Find coordinator, it is very important that you bring all the information you accumulated during the Early Steps program. It is also important to bring your own notes about your child's development, and to ask as many questions as you have about how the school system works and what resources they have available.
- If you don't want to continue with public school, you can always apply for the Gardiner Scholarship offered by Step Up For Students. You can learn more about that program here: <https://www.stepupforstudents.org/for-parents/special-needs/how-the-scholarship-works/>.
- If you need additional Speech Language Therapy you can apply for this grant: <http://www.smallstepsinspeech.org/grant-application/>.
- If you are in Broward County and need more therapy, you can apply at <https://act4me.org>
- IEP: Your child's Individualized Education Plan is guaranteed by the U.S. federal government's Individuals with Disabilities Education Act (IDEA Act). You can read more about this legislation, here:
 - o https://en.wikipedia.org/wiki/Individuals_with_Disabilities_Education_Act#Background_and_historical_context
 - o here
 - o <https://sites.ed.gov/idea/> .

4. IEP (Individualized Education Plan) Meetings:

- The law states that your child's IEP (Individualized Education Plan) needs to be reviewed--and if necessary revised--in an in-person meeting at least once a year. In these meetings, a strategic team is put together with the goal of improving the way school lessons are delivered to your child based on their specific needs. The following people must be in attendance at these meetings: the parent, ESE coordinator, ESE teacher, general education teacher and relevant therapists. Please make sure all teachers and therapists that are working with your child are in attendance at these meetings, or that they provide feedback on how your child is progressing.



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5. After-School Care: Each school has their own after-school program for which you must apply one year in advance to ensure a spot for your child. The website below talks about “reasonable accommodations” under the Americans with Disabilities Act of 1990 (ADA), Section 504. This section can be helpful when asking the after-school program to provide the appropriate care for your child.

- <http://www.fldoe.org/core/fileparse.php/7690/urlt/0070057-sect504.pdf>
- <https://esme.com/resources/special-needs/after-school-program-not-accepting-your-child>

6. Supplemental Resources:

- Waiver from Agency for Persons with Disabilities (APD): This agency provides additional help for parents whose child is in danger in cases where elopement (when a child runs away) or other challenging behaviors are present. If you and your child need this help, don't be afraid to be a persistent advocate for an APD waiver. This waiver allows you to be taken off the waiting list and receive services quickly. Staff from APD will visit your home and investigate your case to see if you qualify for the waiver. If you get in the program you will get Medicaid, but ONLY for your child. You will receive services in either of two ways:
 - o Option 1: Medicaid waiver for respite care, which includes a coordinator to help you.
 - o Option 2: Depending on your case, you might be eligible for CDC+, which is funding that you--not a coordinator--are responsible to manage. For CDC+, you will need to take a yearly class of 40 hours. For more info, please feel free to reach out to us and go to the following websites:
 - <https://apd.myflorida.com/cdcplus/>
 - <https://apd.myflorida.com/providers/enrollment/>
- Social Security and Supplemental Security Income: This is additional help that may be available to you depending on your income; for info on how to apply please go to: <https://www.ssa.gov/disability/>



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7. Choosing Your Therapists: I personally research and interview each therapist before they work with Manu. The best way to look for a therapist is to contact either the ITDS (Infant Toddler Developmental Specialist) that your Early Steps program assigned to you, your service coordinator at Early Steps, or your neurologist. If you work with an ABA therapy provider, make sure they conduct the following assessments: “As BCBA Taylor Thompson suggests the following assessments”

- For very young children I strongly recommend the PEP-3 and/or VBMAPP Assessments.
- For children and young adults who might need more help to learn social and communication skills, please ask the Board-Certified Behavior Analyst (BCBA) assigned by your ABA provider to use the VBMAPP and the MAS assessments. The MAS assessment is essential to understand the reasons why a person with autism behaves the way they do, and, in turn, to help that person become independent and able to communicate their needs.
- For people who are ready for independent living and have some words/language, the following assessments are helpful: ABLLS or AFLLS.

The above assessments are good suggestions, but be sure to follow your Board-Certified Behavior Analyst’s (BCBA) advice.

1. Types of Curricula in Florida: As a parent, you can choose for your child one of two types of curriculum, but you can switch in between them in certain instances, depending on what works best.

- Florida Standards Assessments (FSA) Curriculum, or “For Standards Curriculum”

This curriculum follows a strict timeline, with standardized testing with which your child must comply. Your child will graduate with a diploma that will allow them to be accepted to a 4-year college. For more details, please go to: <http://www.fldoe.org/accountability/assessments/k-12-student-assessment/fsa.shtml>

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- “For Non-Standards/Access” Curriculum (FSAA)

This curriculum focuses on the best strategies to help your child learn at their own pace. This curriculum makes it easier for teachers to develop better ways to deliver lessons or subjects. Your child will graduate with a diploma that will allow them to be accepted to a 2-year college or technical school. For more details, please go to:

https://floridadcdt.org/uploads/3/5/7/1/35718381/inclusion_and_the_florida_access_points.pdf

An FSAA curriculum is helpful when your child is running behind and needs to catch up. However, you have the right to switch to an FSA curriculum at



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1. An Elementary School Example: Manu

Manu is currently in an Exceptional Student Education (ESE) classroom so he can catch up in some of the academic subjects where he is running behind. We are using the aftercare space for Manu to work on his social skills with neurotypical kids with the aid of our ABA therapist, paid by our insurance. The RBT (Registered Behavior Technician) comes to school to work on these social goals. Our ultimate goal is for Manu to be in a mainstream class. (Keep in mind that the state only pays for special services during regular school hours. Aftercare costs extra money, and you have to apply through your child's school around a year in advance.)

1. Middle & High School:

Manu is 8 years old, so I do not have personal experience with middle or high school yet.. However, here are some other resources for parents whose children are further ahead in school.

- Children's Service Council: The Every Parent Champaign offers Palm Beach County parents a unique, local resource full of tips, info and spot-on advice personalized for your family. You can read more here: <https://www.everyparentpbc.org>
- Palm Beach County School District Resources:
 - <https://palmbeachschools.org/cms/One.aspx?portalId=270616&pageId=6395890>
 - https://www.palmbeachschools.org/students_parents/ease/suport_services/transition
- The Arc: Promoting and protecting the human rights of people with intellectual and developmental disabilities and actively supporting their full inclusion and participation in the community throughout their lifetimes. You can read more here: <https://thearc.org>
- The Autism Community in Action (TACA): Various services for people with autism. <https://tacanow.org>
- The Attention Deficit Disorder Association (ADDA) is the world's leading adult ADHD organization: <https://add.org/about-adda/>
- Dyslexia Association: <https://dyslexiaida.org>
- Down Syndrome Association: <https://www.ndss.org>
- Understood: This non-profit helps parents, children and teachers understand neurodiversity: <https://www.understood.org>
- McKay Scholarship: Funding for developmentally disabled children to attend private schools: <http://www.fl DOE.org/schools/school-choice/k-12-scholarship-programs/mckay/>
- Make sure your BCBA and RBT are certified by



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As a conclusion, I would like to leave you with the following things that I have learned are important:

1. to be courageous, perseverant and to trust myself--in other words, to be a loving warrior.
2. to listen, to trust and to apply the advice of professionals, such as therapists, neurologists, ESE coordinators, ESE teachers, and pediatricians.
3. to learn how my child learns and what he likes, and for my ultimate goal to be my child's growth into an independent, unique and loving human being
4. to be the voice of my child, until he finds his own. to stay in the present moment, and to remember that *nothing is written in stone*.

Parents! If you think anything should be added to this document, don't hesitate to contact me at: juonav@manuforinclusion.org.

Sincerely and with all my love
Juana Venegas



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