



By: Bebe Bode

Lightspeed and slo-mo sum up the past 21 years of my life. I always wondered why the good times went as fast as the speed of light and the not so good times felt like they dragged on for 4evah (echo included).

This past December, my first born baby boy turned into a 21-year-old adult. Oh, Lawd in Heaven!

Having a 21-year-old adult son with autism will surely present an array of new challenges for our family... Some we've prepared for, but most will remain a mystery until they happen.

As a parent, I wanted to share 21 things I've learned these past 21 years with the younger generation of parents with hope that it will give you a chance to ponder, prepare and/or plan.

1. **Listen to your inner voice.** If you suspect your child may have a developmental delay or if you feel something is just not right then discuss your concerns with their pediatrician.
2. **Contact Louisiana EarlySteps program.** EarlySteps provides services to families with infants and toddlers aged birth to three years (36 months) who have a medical condition likely to result in a developmental delay, or who have developmental delays.
3. If you learn your child does have a developmental delay, of course, you will be very concerned and may even go through sort of a grieving process. This is normal to an extent. If you find yourself not getting past grieving, **seek help** from a mental health professional.
4. Denial can only last so long before it becomes **detrimental to your child's development and well-being.** The earliest a delay is discovered the better. Early intervention is key in helping your child progress at more age appropriate stages.



FHF of Jefferson
201 Evans Road
Building One, Suite 100
Harahan, LA 70123
504.888.9111
504.888.0246 (fax)
www.fhfjefferson.org



Like us on Facebook:
[Facebook.com/Fhfjefferson](https://www.facebook.com/Fhfjefferson)



Follow us on twitter:
[Twitter.com/FHFofJefferson](https://twitter.com/FHFofJefferson)

5. Remember, the diagnosis of a developmental delay is **not the end of the world**. You can still **dream** for your child, it may look a little different than what your original dreams were, but none the less just as important.
6. **Take action! Learn about your child's disability.**
7. **Call your local Families Helping Families (FHF) center.**
FHF has a center in each Region of the State. FHF centers are staffed with knowledgeable parents of children with disabilities. They can link you to supports and services available in the community as well as educate you about them. (See #13)
8. **Join a support group.** One of the best things I did when I found out my son had autism was joined a support group. I met parents of children who were newly diagnosed, as well as parents of older children with autism. I learned so much from networking with these parents.
9. **Get linked** to supports and services through your local Human Services District/Authority immediately. Some waiting lists for services are very long. To find your local office, visit:
<http://dhh.louisiana.gov/index.cfm/directory/category/145>
10. There is **no magic wand** that is going to "FIX" your child. **Be careful** of any person or therapy that states they can cure your child.
11. **Research** any therapies or services that are recommended or you feel may help your child. Some of the best-recommended therapies can take place in **typical environments with typical peers**.
12. **Take time for yourself.** If you're not taking care of you, then you cannot effectively take care of your family.
13. **Get trained!** When you have a child with a disability services systems and education systems can be hard to navigate. There are also different stages or transitions with both. Your first will be exiting early intervention (for babies and toddlers) and transitioning to school services (for school-aged children). You are not alone! **Families Helping Families of Jefferson is the federally funded Parent Training and Information Center (PTI) for the State of Louisiana.** We provide educational



FHF of Jefferson
201 Evans Road
Building One, Suite 100
Harahan, LA 70123
504.888.9111
504.888.0246 (fax)
www.fhfjefferson.org



Like us on Facebook:
[Facebook.com/Fhfjefferson](https://www.facebook.com/Fhfjefferson)



Follow us on twitter:
[Twitter.com/FHFofJefferson](https://twitter.com/FHFofJefferson)

advocacy, training, and support throughout the entire state.

14. **You are your child's best advocate!** Nobody knows your child better than you.
15. **REMEMBER, you are the most important part of the IEP team. Know your rights! (See #13)** Now that your child is school aged, they will have to go through the school systems evaluation process and meet eligibility criteria for special education services under the Individuals with Disabilities Education Act (IDEA). If eligible, your child's evaluation will drive the services that will be in their Individualized Education Plan (IEP). An IEP is an important legal document. It spells out your child's learning needs, the services the school will provide and how progress will be measured. Several people, including parents, are involved in creating the document.
Don't be afraid to disagree with the IEP team. For more information visit: <http://www.parentcenterhub.org/repository/disagree/>
16. **Special education is a service, not a place.** Just because your child has a disability doesn't mean they cannot be fully included in regular education classes. **Know your rights!**
17. Remember to be **appreciative** of your child's teachers and therapists. Show it by telling them, sending a thank you card or a small gift.
18. Start thinking early on in your child's educational career about what **adult life** may look like for him/her. What diploma or career options are out there? Will he/she be able to attend college? What are my child's interests that may be an opportunity for potential employment?
19. Remove negative people from your life. **Ain't nobody got time for that!**
20. What other people think of you or your child with a disability **DOESN'T DEFINE** either of you. There are some pretty horrible people in this world but there are way more good! I concentrate on the good!
21. **Prepare for the future.** There are many things to consider as you and your child with a disability ages. 1.) Learn about the age of majority (legal status in Louisiana) by the time your



FHF of Jefferson
201 Evans Road
Building One, Suite 100
Harahan, LA 70123
504.888.9111
504.888.0246 (fax)
www.fhfjefferson.org



Like us on Facebook:
[Facebook.com/Fhfjefferson](https://www.facebook.com/Fhfjefferson)



Follow us on twitter:
[Twitter.com/FHFofJefferson](https://twitter.com/FHFofJefferson)

child is 16 years old. http://www.advocacyla.org/tl_files/publications/LegalStatus.pdf 2.) Learn about special needs trusts, visit: <http://www.wrightslaw.com/info/future.plan.index.htm> 3.) Learn about the schools responsibility to your child regarding transition from school to the adult world http://www.advocacyla.org/tl_files/files/Publications/AC%20Transition%20Services.pdf

I hope this list of 21 things can help you as you grow with your child. Of course, there is way more to consider than just these 21 things. Remember, you can always contact your local Families Helping Families with any questions or concerns you have.

We are here to help empower you!



FHF of Jefferson
201 Evans Road
Building One, Suite 100
Harahan, LA 70123
504.888.9111
504.888.0246 (fax)
www.fhfjefferson.org

Changing Lives Every Day



Like us on Facebook:
[Facebook.com/Fhfjefferson](https://www.facebook.com/Fhfjefferson)



Follow us on twitter:
[Twitter.com/FHFofJefferson](https://twitter.com/FHFofJefferson)