

***NEWBORN SCREENING/DIAGNOSIS:
Considerations The Baby Book Won't Tell You***

Presented by:

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But wait...



This baby has a diagnosis and disability may be a part of his/her life.

- This might have been an expected possibility – not a total shock.
- This might have come completely unexpectedly – a total shock.

Regardless, the baby/pregnancy books don't prepare families for this!

Let's talk about what you can do to help them
take important next steps.

A Disability
Label is
ONLY a
Medical
Diagnosis!

Autism
Attachment disorder
AD/HD
epilepsy
Spina bifida
Spina Bifida
OCD
Fetal Alcohol Syndrome
Deaf-blind
CP
Down Syndrome
IDD
Fragile X
LD
TBI
Tuberous sclerosis
Williams Syndrome
Spinal cord injury

YADA YADA YADA...

A
Disability
Label is a
Passport
to Services



The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.

- William James, 1842 – 1910
American psychologist & Philosopher

**“This child will be as disabled
as YOU CHOOSE to see him.”**

~ Pediatric Neurologist as he diagnosed our 3-month old son

Provide

- ✓ knowledgeable
- ✓ up-to-date
- ✓ Reliable
- ✓ accessible

resources!

Or don't!

Provide Connections!

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Texas Parent to Parent

- ❖ Local advocacy or support orgs
- ❖ State/national org representing the child's diagnosis
- ❖ Local ECI Services

Texas Project FIRST - Ages 0-3

Medicaid Waivers – Get them on The List!

Send them here first:

[Navigate Life - TX Waivers explained in Parent Friendly Language](#)

Family/Child does NOT...

- Have to “qualify for services” to get on the list
 - Need to know what services the child will or will not need or qualify for to get on the list.
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- Give families this information in writing
 - suggest a loved one help make the calls (don’t let it get lost in the midst of everything else!)
 - Or make the calls with them!
 - Remind them to update their information annually – especially if contact information/ mailing address changes

DO have a clear conversation with the family about the financial restrictions involved in Medicaid Waivers and Social Security benefits.

This child can never have more than \$2000 in his/her name.



But
remember...Nobody
has a crystal ball. The
experts' job is to paint
the picture that is
possible...as grim as
that might be.

The family's job is to become The Expert on who this child is, to believe in what's possible and to HAVE HOPE for this child and his/her future.





Help family members become Experts

- **Listen** to them
- **Value** their insights, observations,
And questions
- **Teach** them
- **Collaborate** with them
- **Commend** them for what they are
doing well!

Cultivate HOPE.





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