

Opsoclonus Myoclonus Ataxia Family Symposium November 11, 2014



**Texas Children's
Hospital**

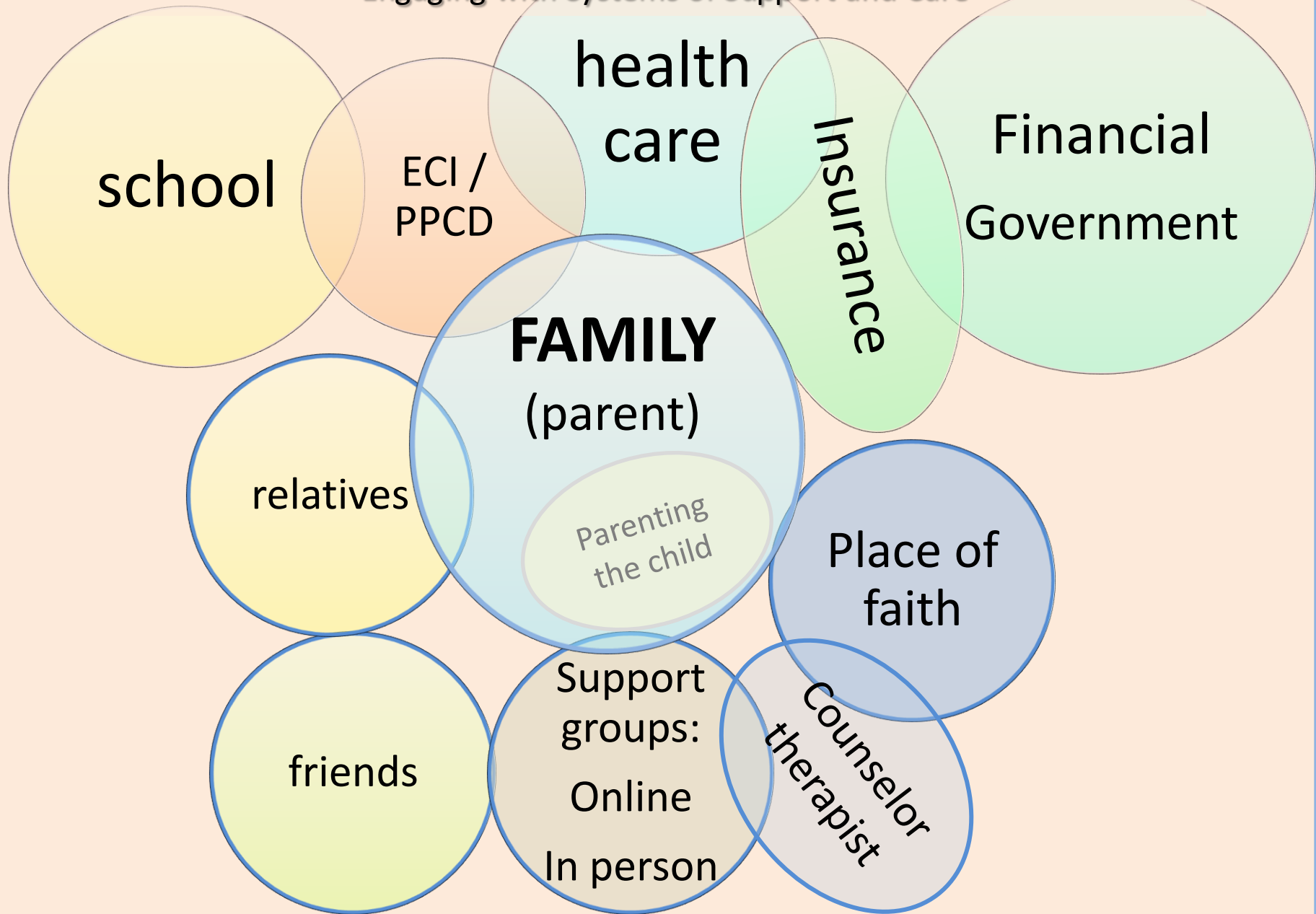
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Developing support for the parents of a child with opsoclonus myoclonus ataxia

- **Goal:** To identify psychosocial supports that will benefit the parent of a child with OMA.
- **Objectives:**
 1. Parent will gain insight into the impact of their child's medical diagnosis on the parent's life
 2. Parent will be able to identify 2-3 supports in their community
 3. Parent will be able to identify 1-2 approaches to increase positive parenting skills

Engaging with Systems of Support and Care



SUPPORT FOR THE PARENT

Research emphasizes the importance of the mother's emotional well-being to assist the child in gaining positive outcomes.

- Support for the parent,
 - notion of medical trauma for some,
 - living in the unknown is a tight rope, balancing btw today and preparing for tomorrow
 - living in the question is **exhausting**



- Natsuaki MN, Shaw DS, Neiderhiser JM, et al. Raised by Depressed Parents: Is it an Environmental Risk? *Clinical child and family psychology review*. 2014;1:1-11.
- Francis A. Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace. *Social Health Illn*. Jul 2012;34(6):927-942.
- Florian V, Krulik T. Loneliness and social support of mothers of chronically ill children. *Soc Sci Med*. 1991;32(11):1291-1296.

Organizing your story so the diagnosis does not become your sole identity *

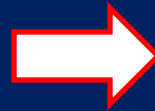


resilience

“My family will never have a normal life.”

“I will always feel overwhelmed.”

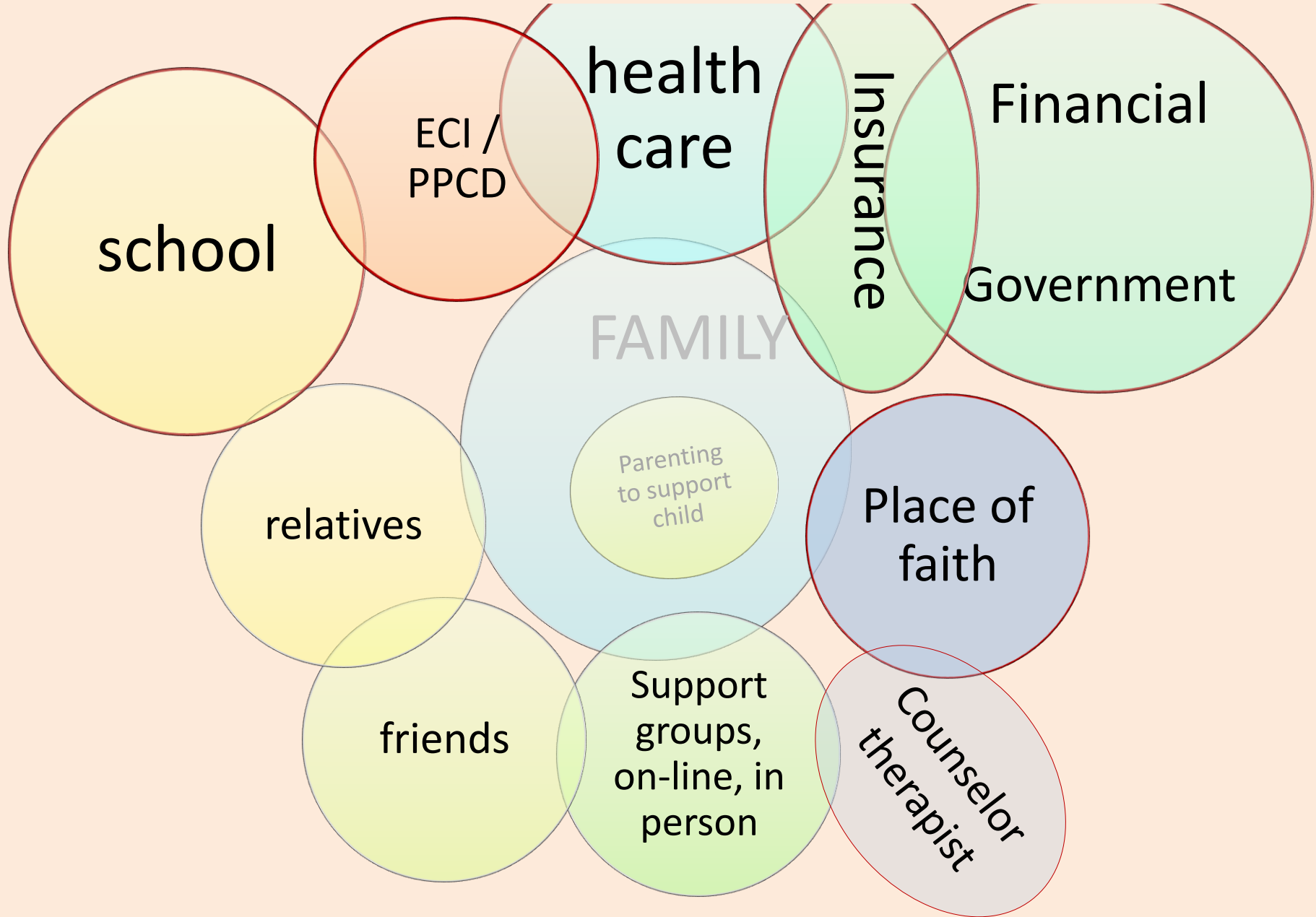
“I can’t cope with this.”



“This is challenging, but we have strengths we can pull on. We can help each other. We are not defined by the diagnosis of OMA.”

- Increase social support
- Increase coping skills
- Increase family communication and functioning as a family unit.
- Refocus *unhelpful* beliefs about OMA and its meanings and consequences by discussion with your medical team

Engaging with Systems of Support and Care



Insurance & SSI

Insurance options

- Medicaid /CHIP
- Private Insurance
- CSHCN (*children with special health care needs*)
- Market Place Insurance (*enrollment November*)
- Indigent care (*differs per county*)

Supplemental Security Income SSI



Level of disability
Compared to peers



Family income inc.
child support and assets

Income Guidelines for CHIP/Children's Medicaid

- 1 Find your family size on the left side of this chart. Follow that row to the right.
- 2 Is your family's income less than the monthly or yearly income shown in the orange Medicaid section?* If so, your children might get Medicaid.
- 3 If your income is higher, follow the row to the green CHIP section. Your children might get CHIP if your income is less than the monthly or yearly income shown in the green section. Children of families that earn higher incomes may also qualify in some cases.

1 Family Members (Adults plus children)	2 May Qualify For Children's Medicaid		3 May Qualify For CHIP	
	Monthly Family Income	Yearly Family Income	Monthly Family Income	Yearly Family Income
1 **	\$1,343	\$16,113	\$2,004	\$24,053
2	\$1,809	\$21,710	\$2,701	\$32,408
3	\$2,277	\$27,324	\$3,399	\$40,788
4	\$2,743	\$32,921	\$4,095	\$49,143
5	\$3,210	\$38,519	\$4,792	\$57,499
6	\$3,678	\$44,132	\$5,490	\$65,879
7	\$4,144	\$49,730	\$6,186	\$74,234
8	\$4,611	\$55,327	\$6,882	\$82,590

*Income is money you get paid before taxes are taken out.

**A family of one might be a child who does not live with a parent or other relative.

Charitable & other resources

- Needymeds.org -> Good Days from Chronic Disease Fund TEL: **877-968-7233**
- Drug companies
- United Healthcare Foundation
- Children's Charity of Texas
- Be an Angel will assist with equipment (eg: a walker)

ECI & PPCD

ECI
Early
Childhood
Intervention
Ages 0 -2yrs



PPCD
PRESCHOOL PROGRAM
FOR CHILDREN WITH
DISABILITIES
3yrs to 5yrs



School system
5 – 18 yrs
(or 21 yrs)

IDEA, 504 plan, OHI, Special Education, Home bound education

Over arching purpose is to ensure that every student receives a free appropriate education.

ARD Admisson Review and Dismissal meeting

- Accommodations
- Modifications
- Assistive technology
- Physical therapy
- Occupational therapy
- Speech therapy
- [Individualized Education Plan \(IEP\):](#)

Resources related to school

- The ARC of Greater Houston

www.aogh.org

- Texas parent to parent

www.parentcompanion.org/

- Disability Rights

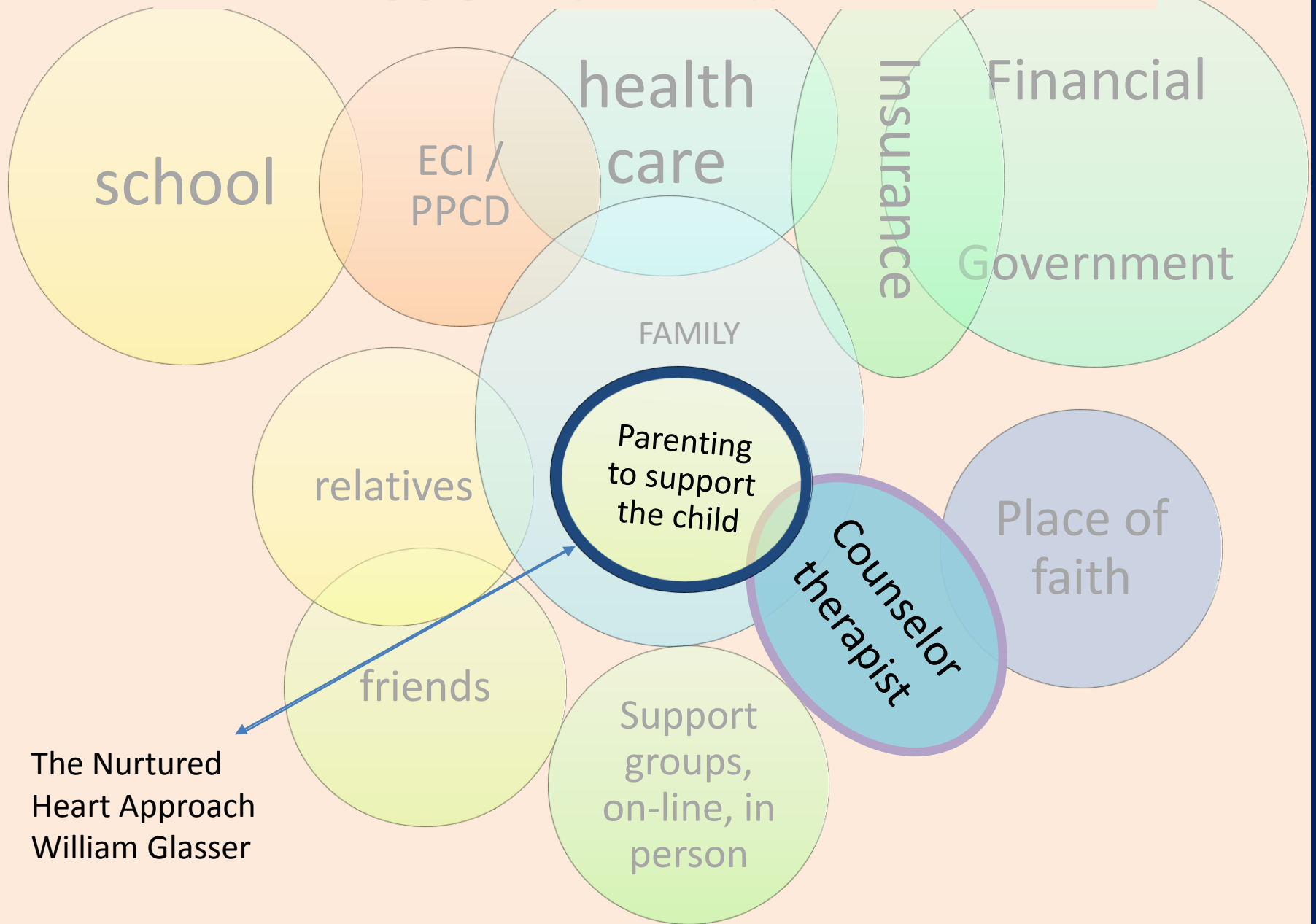
www.DisabilityRightsTx.org

Community supports for the child

- Easter Seals activities
- [Http://socialmotionskills.org/](http://socialmotionskills.org/) (serves Houston)
- Hippo therapy
- Aqua therapy
- Martial Arts such as Kuk Sool or others
- Swimming
- Scouts
- The River arts camp (Houston)
- Fun Fair Positive Soccer (FFPS)

Using natural non competitive activities to place your child in everyday settings

Engaging with Systems of Support and Care



The Nurtured Heart Approach
William Glasser

Create emotional safety



Power struggles are more likely to occur when you:



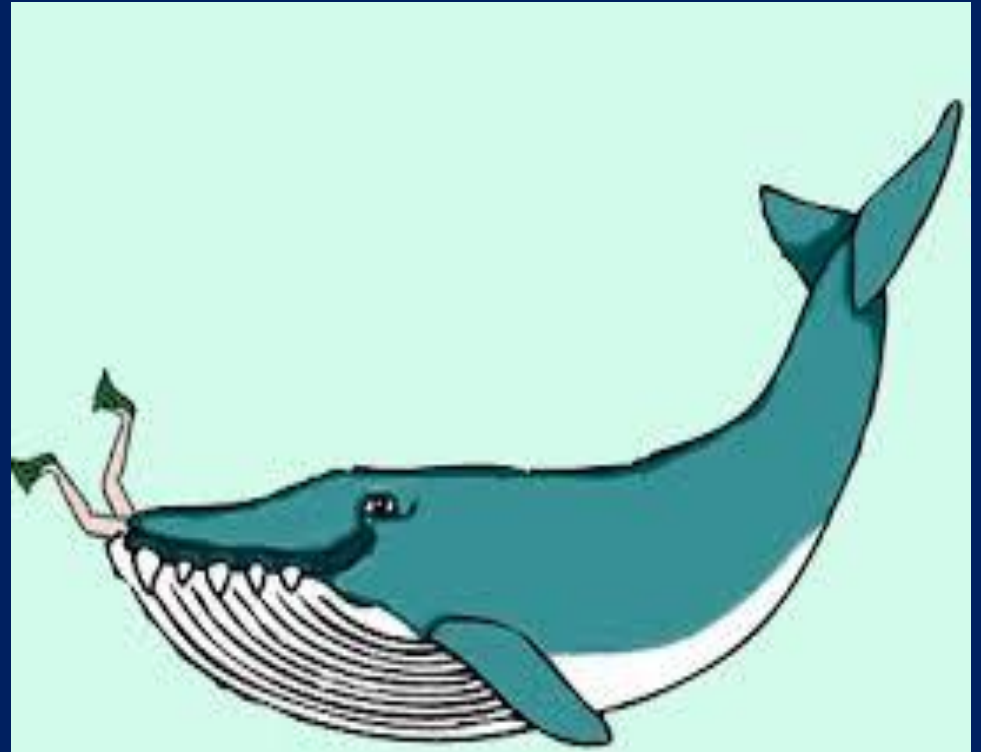
- Have negative perceptions about the child
- See the child as intentionally disruptive or disobedient
- Misinterpret negative behaviors
- Ignore positive behaviors
- Don't maintain appropriate boundaries

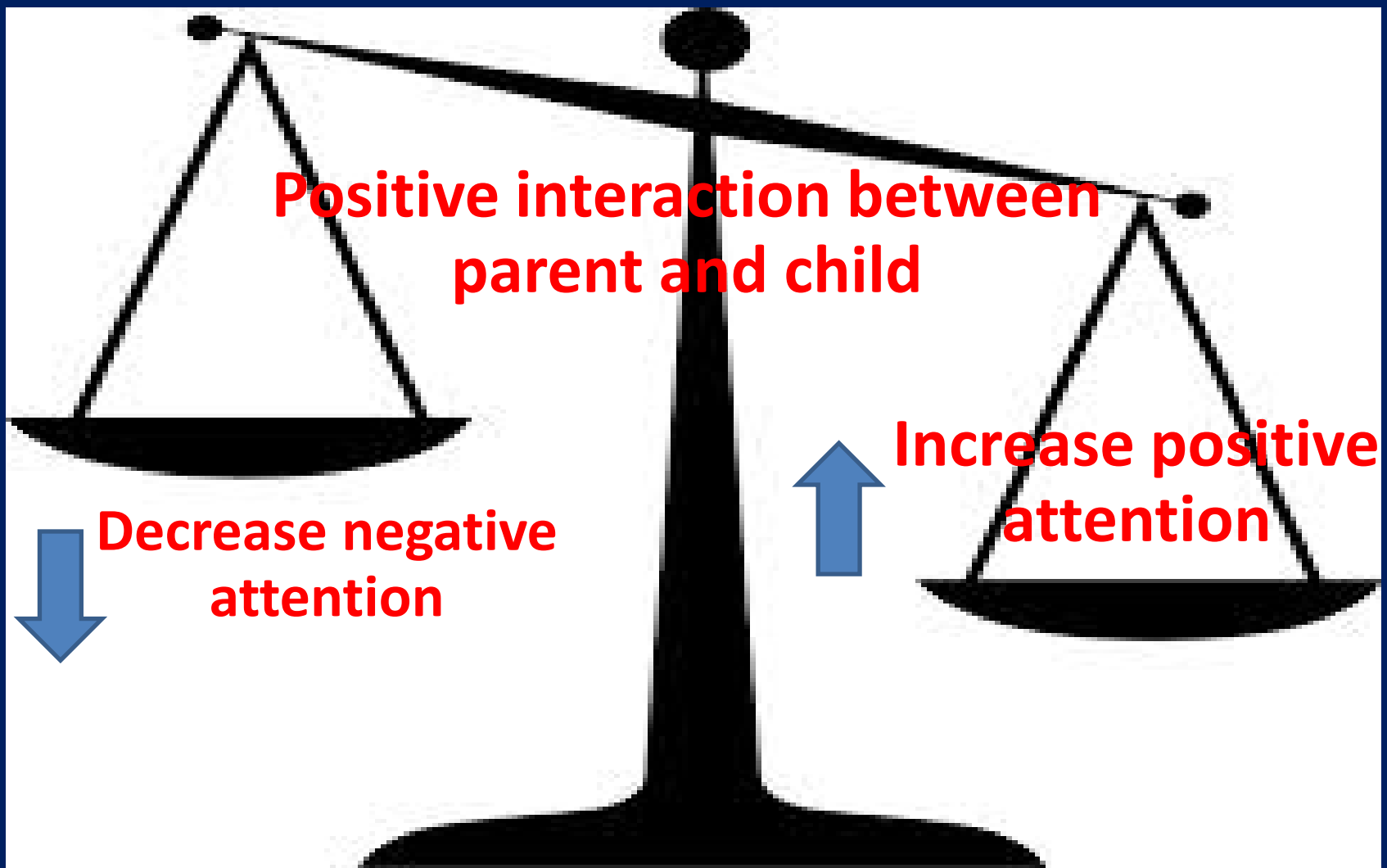


Self Regulation

Time outs

**Don't be
swallowed up**





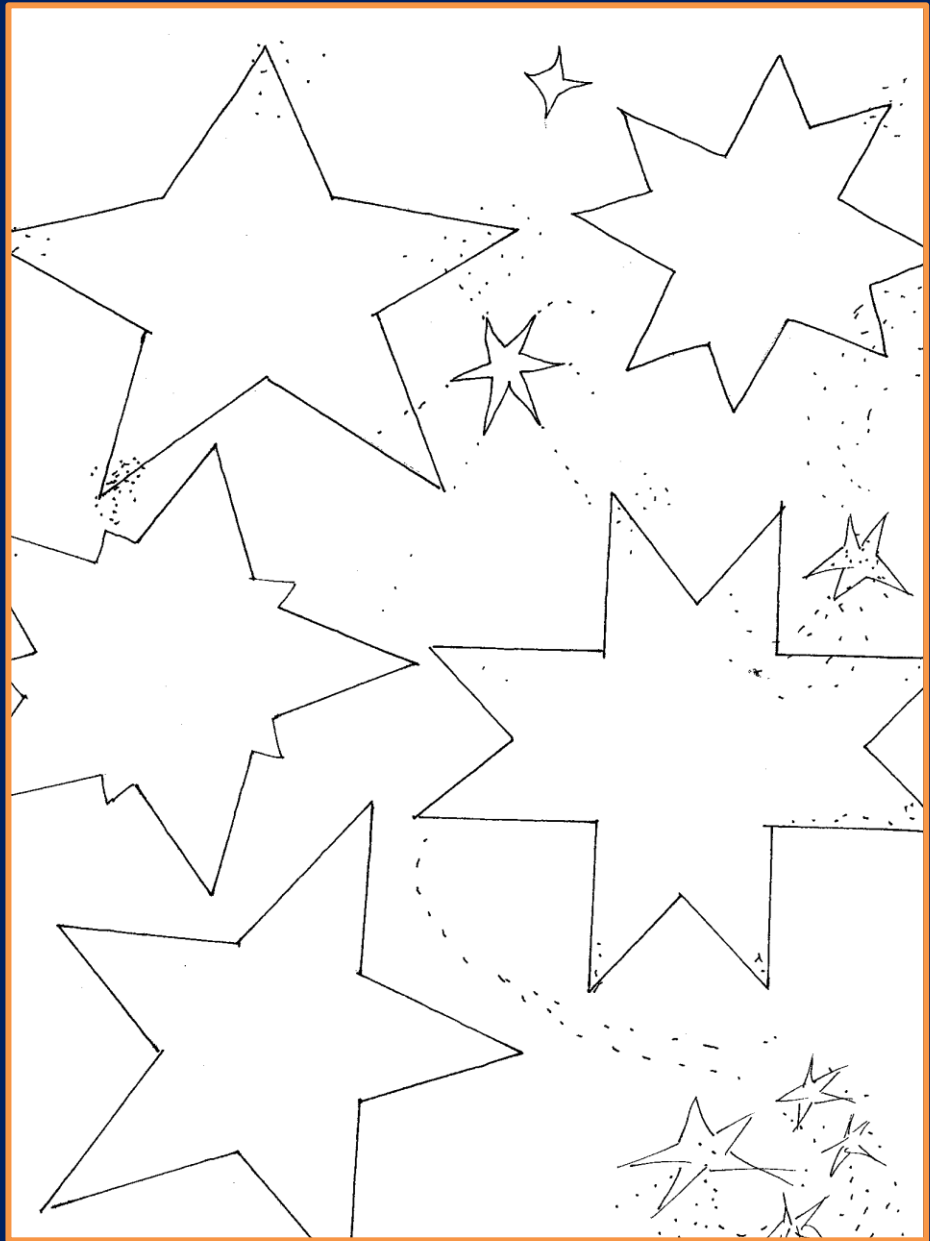
Learn to hold your child in unconditional positive regard

I shine

Hi Diane,

I couldn't come up with anymore negative words for you. I studied xxxxx's every move since last Thursday and each time I tried to envision a negative trait or behavior, I instantly thought of something positive, and literally realized in those moments how this "battle" with OMS has drawn me closer to her.

My point: I don't know if other parents will view this assignment in the same way I did, but even posing the question helped me see things in a different manner. This entire journey has been an emotional roller coaster for both of us, but for all the behaviors that have frustrated me I realize I've had separate what's age appropriate from what may/may not be OMS, and I've had to realize that OMS doesn't shape/define her character, the people around her do...



Sometimes you just have to hold a space

Hold my child in positive unconditional regard

Hold a space that allows imperfection

Allow myself to receive support

Support my child yet be consistent w/
boundaries



There are supports in the system to ease some of our stressors and supports we elect to build into our lives to sustain us on the journey