

Understanding Behavioral Issues in CHARGE Syndrome

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A CHARGE Behavioral Phenotype (first draft)

- Low normal cognitive functioning
- Very goal directed, persistent, and sense of humor
- Socially interested but immature
- Repetitive behaviors; increase under stress
- High levels of sensation seeking
- Under conditions of stress and sensory overload find it difficult to self-regulate and easily lose behavioral control
- Difficulty with shifting attention and transitioning to new activities; easily lost in own thoughts

Diagnoses Piled On

- Autism
- ADHD
- OCD
- Tourette
- Etc.

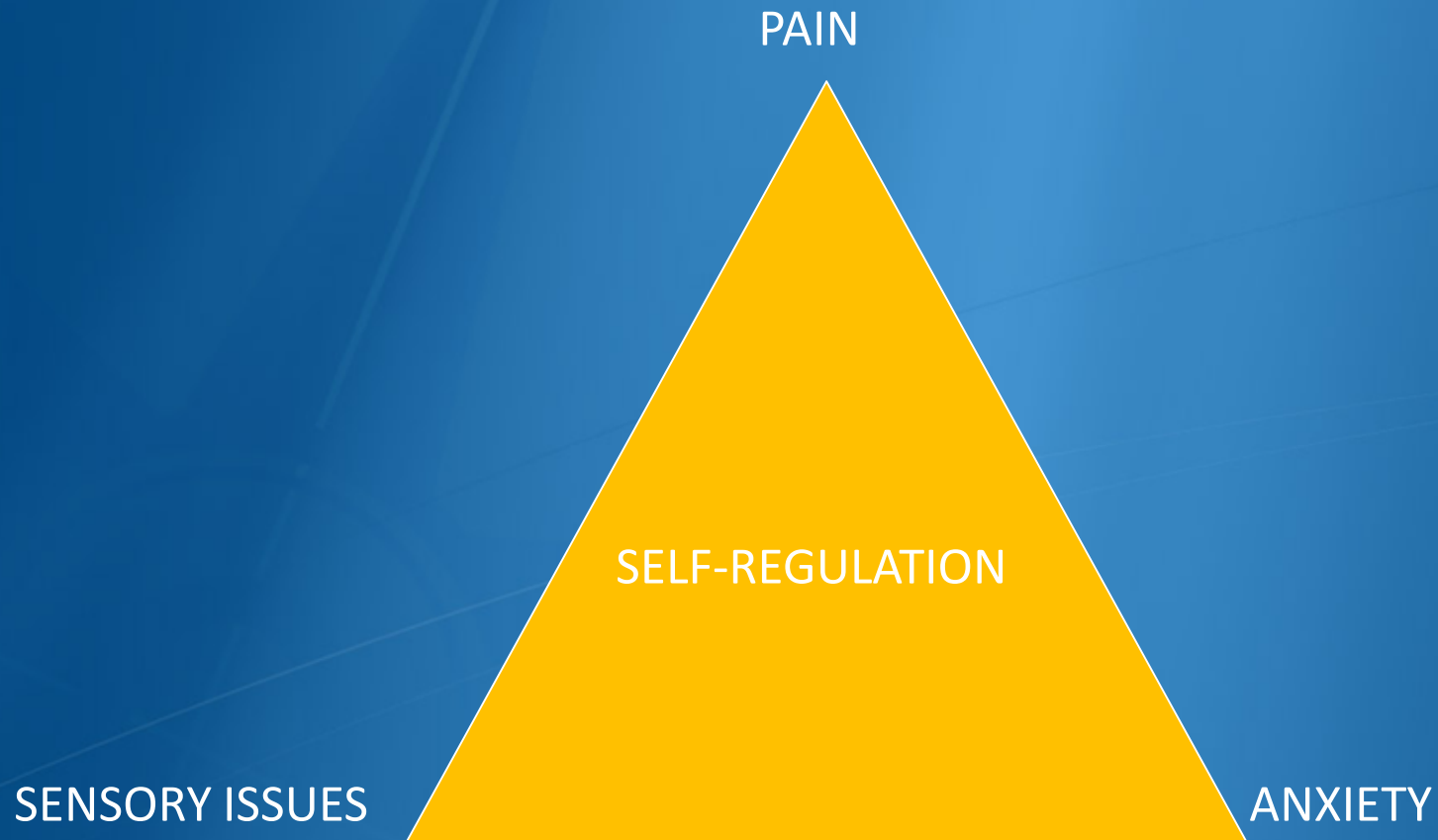


Problems with these Diagnoses

- Create a reality that may not exist
- Lack explanatory value
- Ignore the uniqueness of the behavior
- Lead to multiple drug treatments



The Big Three



Possible sources of pain

- Surgery
- Procedures
- Doctor visits



- Syndrome “related” pain

Sources of Pain in CHARGE

- Otitis Media¹
- Sinus infections
- Migraines¹
- Abdominal Migraines^{1,2}
- Gastroesophageal reflux disease (GERD)²
- Gas
- Constipation^{1,2}
- Muscle pain²
- Tactile defensiveness
- Stoma pain
- Oral pain/teeth
- Surgery¹



Sensory Deficits

- Hearing – sensorineural hearing loss
- Vision – coloboma
- Smell – anosmia
- Taste – prefer strong tastes
- Tactile – defensiveness
- Vestibular – balance issues
- Proprioceptive – awkwardness



This is normal viewing posture...

...when you have no vestibular sense, upper visual field loss, poor tactile & proprioceptive perception, & low muscle tone.





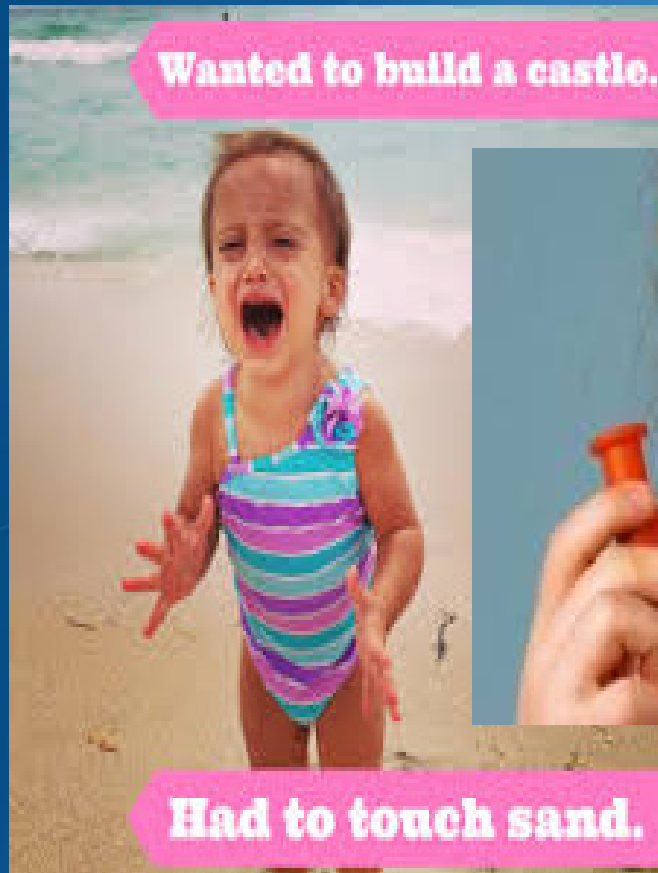
What could
our kids
possibly
have to be
anxious
about?

1. PAIN

It doesn't often
come with a big
sign



2. Sensory overload or underload issues



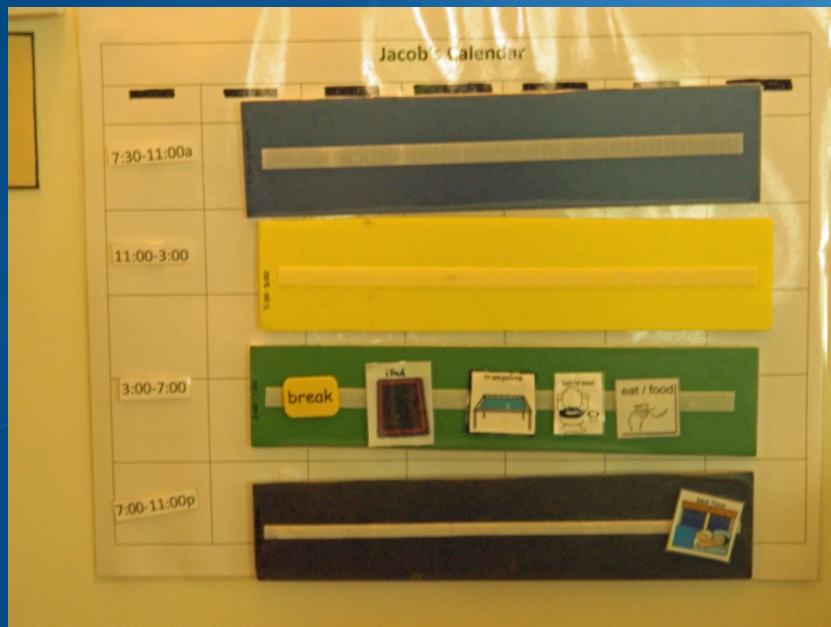
3. Stress

- Life is chaotic.
- I cannot hear/see/balance/predict what's going to happen next.
- I want to escape the chaos.



We like to know what is going on.

- What are we doing right now?
- What are we going to do next?
- What did we just do?



March

April 2015
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