

**FETAL ALCOHOL
SPECTRUM
DISORDER**

*Some Basics
And Caregiver Helps*



An individual's place, and success, in society is almost entirely determined by neurological functioning

- A neurologically injured child is often unable to meet the expectations of parents, family, peers, school and career and can endure a lifetime of failures.
- The largest cause of neurological damage in children is prenatal exposure to alcohol.
- These children grow up to become adults with neurological damage.
- Often the neurological damage goes undiagnosed, but not unpunished.

QUICK Review of Terminology

- Fetal Alcohol Syndrome (FAS)
- Partial FAS (pFAS) Only 1 or 2 facial features.
- Alcohol-related neurodevelopmental disorder (ARND) – no facial features.
- Fetal alcohol effects (FAE) – another catch all term referring to ALL FASD outside of the FAS diagnosis.

FASD “Umbrella”

Impaired Central Nervous System and Neurological Development caused by Fetal Alcohol Exposure

FAS

Facial Features plus neurological impairment

2-10% of cases

a.k.a. FASD w/
Sentinel Facial
Features



FAE

Few or NO facial features plus neurological impairment

90+% of cases

a.k.a. ARND or FASD
w/ NO Sentinel
Facial Features.

Sobering Facts About FASD

- FASD is the leading known cause of preventable mental retardation.
- The CDC on 2/2/16 estimated that up to 1 in 20 school children may have FASD (5%!). They also estimate 2-5% of the population at large (the CDSS estimates this to be nearly 10% in CA).
- NOFAS adds that children in the foster care system are 10-15X more likely to have FASD.
- FASD is more common than autism.
- The effects of FASD last a lifetime.
 - People with an FASD can grow, improve, and function well in life with proper support...

...BUT FASD is a lifetime disability

- It is not curable. A child does not "grow out of it".
- However, early diagnosis and intensive, and appropriate, intervention can make an enormous difference in the prognosis for the child.

Typical Strengths of Persons With FASD

- Friendly and cheerful
- Likable
- VERBAL
- Helpful
- Desire to be liked
- Determined
- Have points of insight
- Hard working
- Every day is a new day!
- Not Malicious



Primary Disabilities With FASD

- Overall Dysmaturity and developmental delays
- Memory Dysfunctions (on & off)
- Attention Deficits (almost universal)
- Auditory Processing Dysfunctions
- Sensory Processing Problems (seeking or avoiding)
- Slower Cognition
- Impulsivity Issues (VERY common & big challenge)
- Learning Dysfunctions
- Not understanding Natural or Logical Consequences
- Difficulty with Abstract Concepts

Secondary Disabilities

Without diagnosis, FASD can create a number of secondary disabilities.

These are entirely PREVENTABLE.

They are the results or consequences of having to deal with their primary disabilities.

SO, if they are dealt with better, less secondary issues.

SECONDARY DISABILITIES

In Individuals with **Undiagnosed or Improperly treated FASD**

- 95% will have mental health problems
- 68% will have "disrupted school experience"
- 68% will experience trouble with the law
- 55% will be confined in prison, drug or alcohol treatment center or mental institution
- 82% will not be able to live independently
- 70% will have problems with employment

Factors That REDUCE Secondary Disabilities

- Stable home
- Recognized disabilities
- Early diagnosis of FASD
- Appropriate Intervention
- No violence against the child
- Good quality home from ages 8 to 12
- More than 2.8 years in each living situation
- Basic needs met for at least 13 percent of life

Identifying FASD

Only trained professionals can truly diagnose a disorder from the FASD spectrum. Ideally, diagnosis is done by a team that may include:

- > Geneticists
- > Developmental pediatricians
- > Neurologists
- > Dysmorphologists (physicians specializing in birth defects)
- > Education consultants
- > Psychologists, psychiatrists, and social workers
- > Occupational therapists
- > Speech and language specialists

Trends in Treatment

Strategies to assist persons with FASD and their families continue to increase dynamically:

- Recent discoveries in brain and neurological research in the last 3-5 years have uncovered some VERY encouraging discoveries. Of particular note are the critical effects of *attachment* and *Neuroplasticity* in showing us how the brain can “rewire” itself when there is a close connection to a loving and stable caregiver.
- This brain science has influenced and created some proven techniques for parents and caregivers to use to help redress many aspects of neurological impairments.
- One of these strategies is called *Trust Based Relational Intervention (TBRI)* which also provides proven help in working with FASD in children as well as many other types of neurological conditions. [See EmpoweredtoConnect.org](http://EmpoweredtoConnect.org)

The Benefits of Identification and Treatment of FASD

- **Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful.**
- **Helps people with an FASD succeed by focusing on their strengths and what will help them, not on their ‘weaknesses’ and what they’ve done ‘wrong.’**
- **Helps improve outcomes.**



HOPE & Parenting Helps For Dealing w/ FASD

- Grief & Loss
- WE have to think differently
- Create NEW hopes & dreams
- Dealing with Burn Out
- Know What WORKS & What DOESN'T
- SUPPORT RESOURCES

Grief & Loss

- Loss of Hopes & Dreams

You're making it difficult for me to be the parent I always imagined I would be.



someecards
user card

WHAT I THOUGHT PARENTING
WOULD LOOK LIKE...



WHAT IT'S LIKE.

Grief & Loss

- Loss of Peace in the home and family (marriage and sibling relationships)
- Loss of ability to revel
- GRIEF REQUIRES ACCEPTANCE TO MOVE FORWARD IN A HEALTHY MANNER

Thinking Differently & Adapting Expectations

Former View

Won't
Bad
Lazy
Lies
Doesn't try
Fussy; demanding
Trying to get attention
Acting younger
Thief

New View

Can't
Frustrated, challenged
Tries hard as he can
Confabulates, fills in
Tired of failing, exhausted
Oversensitive
Needs contact or support
IS developmentally younger
Doesn't understand ownership or impulsive

Create NEW hopes & dreams

- Redefine Success!!
- With greater awareness, draw NEW dreams and cling to them! Draw strength from them!
- DO NOT FORGET THEM!!



Dealing with Burn Out

- What is it?
 - *“Chronic failures associated with the discrepancy between the perceived ability of the individuals living with FASD and their actual ability or performance creates burnout. It is a process that takes time and likewise, recovering emotional resiliency takes time.” Diane Malbin*
 - **Jeff Noble**, “We don’t experience burn out because those with FASD couldn’t perform what we expect just once – we experience burn out from feeling let down and disappointed by them over and over again.”

Dealing with Burn Out

- What are some of the symptoms of burn out:
 - Exhaustion of physical & mental resources.
 - Wearing yourself out by excessively striving to reach some unrealistic expectation imposed by yourself or others.
 - Prolonged discomfort including anger and fear.
 - Increasing frustration and decreasing tolerance.
 - Feeling unappreciated: anger & resentment and disillusionment.
 - Depression, denial of feelings, relationships suffer

Another HUGE Cause of Burn Out

- DO NOT EVER COMPARE YOURSELF TO OTHER PARENTS!
- EVEN OTHER PARENTS OF CHILDREN WITH FASD!
- Tyranny of Success

remember
you **DON'T**
have to explain your
family's parenting
choices to
ANYONE.

These things can prevent Burn Out

- Pick your battles & know your triggers
- Protect relationships with spouse & other children
- VENT!
- Go for a walk/exercise!
- RESPITE!



Know What DOESN'T Work

- CONNECTION with your child is EXTREMELY important. It really is the key to everything.
- **Appropriate expectations are also VERY critical.**
- Parenting methods like T.B.R.I. and Nurtured Heart are effective.
- **BUT many parenting ideas and practices do NOT work well or at all.** (consequences, tough love or other traditional style parenting that uses punishment as a behavior control or training method will fail miserably. *Because it requires a healthy brain to work.*
- Holding them responsible for behavior they cannot control DOES NOT work.

What Works

- **Focus on Changing the ENVIRONMENT not the behavior.** (cause the behavior won't change)
- **Simplicity** (less is best!)
- **External Brain**
- **Supervision and Structure** (VERY important)
- **Enabling** (even bribing)
- **Normalizing**
- **Helping them develop good habits**
- **Individualize!!!**

SUPPORT RESOURCES

- Online
 - Samhsa & Faslink (www.samhsa.gov/ & www.faslink.org/)
 - Nofas & FASD Forever (www.nofas.org & fasdforever.com)
 - Transformational Family Ministries (www.tfmnotalone.org)
- Recommended Reading
 - The Connected Child, Drs.Purvis & Cross
 - Making Sense of the Madness, Jeff Noble (of FASD forever)
 - Whole Brained Child, Dr. Dan Siegal
 - Out of Sync Child, Dr. Carol Stock Kranowitz
 - Trying Smarter Not Harder, Diane Malbin
- Support Groups
 - FASD Sac Valley (fasdsacvalley.wordpress.com/what-is-fasd/)
 - Norcal FASD (www.fasdnorcal.org/)
 - Yolo County Post Adoptive Support (www.lilliput.org › Services)



**Thank you for taking time
to learn about FASD!**

For more information see our website
www.tfmnotalone.org
